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FINAL EVALUATION AND STATUS REPORT

OF A FOLLOW UP SURVEY OF

MENTALLY ILL PATIENTS RELEASED FROM

WARM SPRINGS STATE HOSPITAL

The Office of the Governor Thomas L. Judge, Governor

Office of Budget and Program Planning

George L. Bousliman, Director



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FINAL EVALUATION AND STATUS REPORT

of a

FOLLOW UP SURVEY OF A SAMPLE OF MENTALLY ILL

PATIENTS FROM WARM SPRINGS STATE HOSPITAL

WHO WERE RELEASED TO COMMUNITY SERVICE

PROGRAMS PRIOR TO FEBRUARY, 1977*

Submitted by:

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FINAL EVALUATION REPORT

of a

Follow-up Survey of a Sample of Mentally Ill Patients from Warm Springs State Hospital Who Were Released to Community Service Programs Prior to February 1977

for the

Office of Budget and Program Planning

of the

Office of the Governor of the State of Montana

The information presented in this report was collected and compiled for Office of Budget and Program Planning (OBPP).

This report represents an evaluative summary and assessment of the level and quality of care and rehabilitation efforts currently being received by a sample of mentally ill persons, who have been placed in community settings throughout the State of Montana.

The purpose of the study was to:

- l. Identify a representative sample of patients who were deinstitutionalized patients from WSSH.
- 2. Provide followup on this group of individuals to determine whether treatment plans were prepared and carried out.
- 3. Determine if the needs of the deinstitutionalized patient are met by this placement in the community.
- 4. Determine what treatment procedures were used once the patient was placed in local communities.

5. Determine, by the use of an acceptable measuring instrument, whether the patient is capable of adjusting to his community placement.

This evaluation contains six major sections:

- 1. Section One provides a profile of demographic information of those patients who have been released from Warm Springs State Hospital (WSSH) and included in this survey.
- 2. The Second Section covers individual client data which was extracted from the Mental Health Center files.
- 3. The Third Section provides information relative to the site in which the patient was placed.
- 4. Section Four addresses itself to the type of training received by the patients once they were placed.
- 5. Section Five reflects the data obtained from the Adaptive Behavior Scale.
- 6. The Sixth Section presents the summary, conclusions and recommendations.

I. WSSH CLIENT DEMOGRAPHIC

DATA SUMMARY

A DEMOGRAPHIC PROFILE of the DEINSTITUTIONALIZED PATIENT

Sample

The sample for this survey consists of fifty-eight patients who were released from WSSH prior to February, 1977. After reviewing a computer printout of the patients who were released, it became obvious that the majority of them were placed in sites located in Regions III and IV. To make the sample more representative of actual placement patterns, a decision was made to include a higher number of patients from those two regions. Fifteen patients each from Region III and IV were included in the survey sample. Representation from throughout the State had to be assured so ten patients each from Regions I, II, and V were then included in the survey sample.

A systematic, random sample was then drawn from the computer printout.

The total number of persons released to each region was divided by the number of patients to be included in the sample. In Regions III and IV, the first and every 15th name was included; and in Regions I, II, and V, the first and every 10th name was included in the survey sample, thus assuring a systematic random sample. An additional criteria for inclusion in the sample was established. To meet the spirit and intent of deinstitutionalization, a patient must have been hospitalized at least three years or longer.

In drawing the sample, an assumption was made: That WSSH released patients according to established criteria and therefore no inconsistency in the

process of deinstitutionalization existed. WSSH estabilished as a standard for release that the patients had received maximum hospital benefits.

With established criteria and specific names, the evaluation team extracted data directly from client files. The sample was reduced by two because one patient left the state after he was released and another was deceased.

An example of the worksheet used in extracting the demographic data is found in Appendix A. Appendix B contains the Raw Demographic Data Code Identification Numbers and Titles.

Age

The age of the fifty-eight sample patients ranged from a high of 95 years to a low of 22 years. The mean age of the patients was 65.6 years. Thus, the sample represents an elderly population.

Sex

The sex of this group was evenly divided. Twenty-nine (50%) of the fifty-eight patients were male and twenty-nine (50%) were female. This separation was not by design but occurred by chance.

Marital Status

Thirty patients (51.7%) were single, ten patients (17.2%) were divorced and eleven (19.0%) were married. Three patients (5.2%) were widowed and there was no data regarding the marital status of four patients (6.9%).

Occupation

Twelve patients (20.7%) never worked. Thirteen (22.4%) worked as laborers (ranch, farm and construction). Two each worked in domestic

services, mining, teaching and as painters, accounting for 15% of the sample. There is no knowledge of whether eight patients (13.8%) even were employed. The remaining patients worked in jobs such as bartending, waitress and sales work, cook and telegrapher.

Family Members

According to hospital records, nine patients (15.52%) did not know whether they had family members. Two patients (3.4%) had none, twenty-four (41.4%) had one, twelve people (20.7%) had two and five individuals (8.6%) had three family members. The remaining 6 patients (10%) had more than three family members.

Type of Commitment

From the data collected, a person could be committed to WSSH for four different reasons. Three people (5.2%) in this sample were committed by court order. If a patient is committed for this reason, he has been involved in criminal activity and has been ordered to WSSH by a judge. Twenty-two people (38%) were voluntarily committed. Under this type of commitment, the patient has volunteered to enter WSSH for treatment. Thirty-one people (53.4%) received a standard commitment. It was necessary for two physicians to certify that the patient was mentally ill in order to confine an individual under the standard commitment clause. Two people (3.4%) were committed for emergency reasons. For a patient to be committed for the above reason, there must be no facilities in the local community to safely confine the person and formal commitment procedures must have been immediately initiated.

To make the data more meaningful, it was decided to present the times

patients (13.8%) were hospitalized. During the 1930's, nine patients (15.5%) were placed in WSSH. From 1940 to 1950, four individuals (6.7%) became WSSH patients. In the 1960's, eighteen patients (31.0%) were hospitalized; and in the 1970's, eleven patients (19.0%) were hospitalized.

Number of Previous Commitments

Many of the patients in this sample were hospitalized only once. Forty-one people (70.7%) had had no previous contact with WSSH, five people (8.6%) had had one previous visit, eight people (13.8%) had had two previous visits, three people (5.2%) had had three previous visits and one person (1.7%) had had four previous visits to Warm Springs.

Diagnosis at the Time of Entry Into WSSH

The diagnoses of patients are too numerous to discuss on an individual basis. Twenty-seven different diagnosis are given. For the sake of clarity, only those most frequently used will be highlighted.

- 1. Thirteen patients (22.4%) had the diagnosis of schizophrenic reactions, chronic undifferentiated type.
- 2. Five patients (8.6%) received a primary diagnosis of schizophrenic reaction, simple type.
- 3. Five (8.6%) had a diagnosis of paranoid schizophrenia.
- 4. Four (6.9%) had the label of schizophrenia, catatonic type.
- 5. Three patients (5.2%) were hospitalized for mild mental retardation.
- 6. Three individuals (5.2%) were non-psychotic, but had an organic brain syndrome with brain trauma.

Reasons for Hospitalization

Hallucinations, delusions, disorientation, violence and the inability to care for oneself were the most prominent reasons for a patient to be hospitalized. Seven patients (12.1%) were hospitalized for having hallucinations, six persons (10.3%) for delusions, six persons (10.3%) for disorientation, five persons (8.6%) for violence, and six persons (10.3%) for inability to care for themselves.

In addition to the reasons given above, others, such as drug addiction, incompetency, senility, and epilepsy also were listed. Two patients (3.4%) in each of those categories (13.6%) were hospitalized for those reasons.

Location of Release

Upon release from WSSII, the majority of patients were placed in cities/
towns within the region of their original home sites. However, as placements
were made, most (75%) were placed in nursing homes in or adjacent to their
home towns. Butte and Billings received the largest number of clients, twelve
and nine respectively. The other patients, one, two or three in number, were
placed in one of twenty-two other towns/cities around the state. Release
locations were undeterminable for two persons.

Medication Upon Release

Nearly 100% of the patients were on medication at their time of release. The medication most frequently used was Artane (17.2%), Vitamin C (13.79%), Stelazine (17.2%), Thorazine (13.8%), Mellaril (15.5%) Serentil (10.3%), Dilantin (10.3%), Tritafon (12.0%) and Phenobarbital (8.6%). Many patients were using more than one drug and the dosages of the medication varied with each person. A total of seventy-four different drugs were used in treating patients while they were in the hospital.

Treatment Plan at WSSH

The sample patients at WSSH often received more than one type of treatment regime so the percentages reported will exceed one hundred percent in this category.

Chemotherapy was listed as a treatment 56.9% of the time. This was the most frequent choice of treatment. Milieu therapy was prescribed for 46.6% of the patients. Activities of daily living and recreational therapy were given to four patients respectively, accounting for 13.8% of the sample. Supportive counseling was prescribed to nine patients (15.5%). Occupational therapy was prescribed for four patients (6.9%), group therapy for five people (8.6%).

In addition, custodial care was recommended for nine patients (15.5%). No treatment was prescribed for seven people (12.1%), and for 10 people (17.2%) the plan of treatment was unknown.

Treatment Plan Upon Release

The treatment plans for those who were released from WSSH included chemotherapy for fourteen patients (24.1%), nursing home placement for

thirteen people (22.4%), rest or convalescent home for twenty patients (34.5%) milieu therapy for six people (10.3%), group home placement for four individuals (6.9%) and supportive counseling for four people (6.9%).

It must be remembered that more than one type of treatment probably would be recommended for a patient so the percentages will not equal one hundred percent.

At the time of release from the WSSH, the length of patient institutionalized time ranged from three to fifty-three years. The average length of stay for all clients in the sample was 19.93 years. Twenty patients (49%) were noted to have spent 30 years or more at WSSH prior to release.

II. INDIVIDUAL CLIENT DATA:

MENTAL HEALTH CENTER FILES

PART II

INDIVIDUAL CLIENT DATA: MENTAL HEALTH CENTER FILES

The information presented in this section was derived by conducting a direct and thorough review of each patient's active file, contained within the record keeping system maintained by the respective Mental Health Center Regional Office and/or their satellite offices.

From the original target population (N=58) drawn randomly from WSSH computerized patient release data forms, the study team was able to locate and analyze files on a total of forty-one (41) released patients. The following describes the shift in samples from an N=58 to an N=41. A breakdown by Region follows:

- Region I, original list contained nine patients, one transferred out of the state and five were transferred to other regions. Net, N=3.
- 2. Region II, original list contained nine patients, one died and three were transferred to other regions. Net, N=5.
- 3. Region III, original list contained fifteen patients, three transferred to other regions. Net, N=11.
- 4. Region IV, original list contained fifteen names. Net, N=15.
- 5. Region V, original list contained ten patients, three transferred to other regions. Net, N=7.

Thus, file reviews on individual clients can be broken down as follows:

- 1. Region I, 3 of 9.
- 2. Region II, 5 of 9.
- 3. Region III, 11 of 15.
- 4. Region IV, 15 of 15.
- 5. Region V, 7 of 10.

Four additional patients were located within assigned regions following release from WSSH, but had no files that could be located within the existing regional Mental Health Center records. Two of those lients were in Region III and two were in Region V. The following is a narrative summary of the information obtained by reviewing the 41 individual client files (Table 1).

Clients' ages, education, current residence and marital status can be summarized as follows: Ninety percent (37) of the patients were over 50 years of age and sixty-six percent (27) were over 60 years of age. Thirty-nine percent (16) were over seventy years of age. Sixty-one percent (25) had less than a high school diploma. Four patients, (approximately 10%) had completed one or more years of college but none held a four-year degree. The educational status for eight patients (19.5%) was unknown/no data available.

The review of the current residence of the released patients find most (78%) residing in nursing homes. Six (16%) currently resided in group homes, one was in a foster home, one was living with his/her natural family and one was living independently. A look at marital status revealed most (21) to be single (51%), eight (20%) were married, and eight (20%) were divorced, and three (7%) were widowed. No data was available for one client (2%).

Responsibility for patients upon release was most commonly (N=16) assigned to the patient himself/herself (39%); two percent (1) had a legal guardian recognized; and for thirteen clients (32%) responsible parties were not identified in the files. In the case of eleven patients (27%), parents, close relatives or spouses were the responsible parties.

A review of employment information revealed that one person was actively employed (greater than 50% of the time) and one person was engaged

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TABLE I - INDIVIDUAL CLIENT DATA

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in part time (less than 50% of the time) employment. Ninety percent of the clients (37) were unemployed and data was unavailable for two persons.

Release data indicated that thirty patients (73%) were discharged to nursing home settings and that another twenty percent (8) were placed in group homes. Foster home placement, natural home placement or an independent living situation was the initial placement for one patient each. Further analysis reveals that thirty-eight (93%) have continued in their original placement. Two patients (5%) have undergone two or more placement changes and one patient was returned to WSSH.

The review of individual client files revealed that forty-one patient files contined a statement of primary diagnosis (100%); six contained statements of secondary diagnosis (15%) and fifteen files (37%) contained statements regarding patient prognosis. Medication levels for patients following release have followed a mixed pattern with thirty-four percent (14) requiring increased dosages, thirty-two percent decreased dosages, twenty-nine percent no change and five percent (2) having insufficient data.

For sixty-eight percent of the sample (28 persons), the files contained specific treatment plans with long range goals. Thirty-two percent of the files contained no treatment plans and goals. Intermediate objectives for treatment were again found in sixty-eight percent of the files and absent in thirty-two percent of the cases. Only twenty-four percent of the files (N=10) had training programs with specific provisions for continuous assessment and evaluation.

In reviewing MHC client files, twenty-six patients (63%) had been assigned case managers by the Mental Health Centers. Fifteen patients (27%) had not

been so assigned. These case managers were mental health workers (39%), psychiatric nurses (15%), clinical psychologists (5%) and group home supervisors (7%). Case manager contacts with patients upon release were centered around follow-up and maintenance (20%), home visits (17%), group therapy (7%) and placement services (7%). Thirty-four percent of the patients had no case managers and/or no contacts with case managers. Contacts between case managers and patients varied greatly in terms of frequency. Thirty-two percent (13) were scheduled monthly, twenty percent were daily and the remainder were bi-monthly or as needed (Table II).

Interviews with case managers regarding adequacy of follow-up revealed the following:

- 1. The majority of the clients (61%) were regarded as suitably placed and receiving sufficient follow-up.
- 2. Follow-up was questionable for two patients (5%).
- 3. Fourteen of the patients (34%) were receiving no follow-up.
- 4. Case managers felt that two patients could have functioned well in a less restrictive placement.

Case managers were able to identify a number of specific patient related problems in client follow-up and placement. These included physical problems (5), communication problems (6), lack of therapeutic service (3), lack of client participation (2) and legal problems (2). Eight clients were reported as having presented no problems and again, in fourteen cases, there were no managers (34%) and no available manager data.

Ongoing service contacts and contractual arrangements between clients and WSSH personnel were limited. Twenty-six clients received no continuing

TABLE II - CASE MANAGER DATA MENTAL HEALTH CENTER FILES

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TABLE II - CASE MANAGER DATA
MENTAL HEALTH CENTER FILES

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TABLE II - CASE MANAGER DATA
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support service and fourteen clients had no case manager assigned.

Communication and information sharing between WSSH and Mental Health
Centers regarding patient placement was viewed by case managers in the
following manner:

- 1. Sufficient communication prior to placement (10%).
- 2. Insufficient information prior to placement (12%).
- 3. Sufficient information accompanying actual placement (7%).
- 4. Insufficient information with actual placement (17%).
- 5. No communication and information from WSSH (10%).
- 6. No case manager (34%).

III. PATIENT RESIDENTIAL DATA
SUMMARY

PART III

PATIENT RESIDENTIAL DATA SUMMARY

The information included in this section of the report is divided into two major parts. The first part presents descriptive information regarding the clients in-residence status, data regarding the location and nature of the residence, and information on client service, resources and programs as identified within the residential setting. Part two of this section presents a brief description of the supervisory personnel involved with individual clients within each setting.

Although a portion of this data is somewhat repetitive of data presented in other sections, it was obtained directly from the residential programs themselves and does contain new and specific pieces of information regarding clients/patients not presented elsewhere. Information in this section was obtained via direct, on-site visitation with patients, residential personnel and observations.

IN-RESIDENCE PATIENT STATUS

Forty-five patients were studied in this portion of the follow-up study.

Eighty-two percent of the clients were toilet trained and eighty-seven were ambulatory. Seventy-six percent were able to dress themselves and ninety-one percent could feed themselves. Requirements for patient supervision varied greatly with individual clients. Twenty-seven percent required constant supervision, forty-six percent required moderate supervision and twenty-seven percent

required only minimal supervision. The distribution of patients across residential settings was as reported earlier in this report (Table III).

The majority of patients (78%) was not found to be involved in any specific in-residence training programs; however, two percent each were enrolled in educational and sheltered workshop programs, five percent were in activity center/avocational center programs and thirteen percent were in day care programs. The availability of these programs varied greatly from community to community. Thirty-three percent of the clients were living in communities of 10,000 - 20,000, twenty-five percent in communities of 25,000+ and twenty-nine percent lived in communities of less than 5,000 persons.

RESIDENTIAL SETTING

The majority of the residential facilities (84%) were located in middle or upper income neighborhoods according to residence supervisors.

Advisory Boards (selected community representatives) were found to be actively involved in the residential settings of eighty-four percent of the patients. Ninety-six percent of the residential settings had specific provisions for home visitations. Twenty-four percent of the patients were viewed as capable of making unescorted trips to and from the home with the remainder (76%) requiring escorts and/or supervision (Table IV).

Ninety-eight percent of the patients were limited or restricted in terms of personal possessions. Although twenty percent of the patients lived in settings providing the earning of money, in eighty-nine percent of the cases these clients were not permitted to manage their own monies. Sources of client income included Social Security payments, retirement pensions, medicaid, family or private trusts, state and federal training program monies.

TABLE III GENERAL DEMOGRAPHIC SUMMARY - RESIDENTIAL DATA

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The majority (87%) of the residential settings served meals family style. The patients were served meals in a common dining room and food was brought to each table and the patients served themselves. Client clothing was individually owned (100%) and each person had a private storage area or closet.

Ninety-one percent of the patients shared a room with other patients and all but one had his/her own bed. The individual sharing a bed was in residence in his natural home. Four patients had private rooms within their institutional setting.

Fifty percent of the patients had general access to telephones for incoming and outgoing calls and fifty percent of the patients were allowed to freely send or receive mail. Seventy-six percent of the patients were reported as not having the opportunity to participate in residential facility policy and procedures formulations. (Table IV).

RECREATION

The majority of residential settings offered the patient access to a wide variety of activities, recreational events and celebrations. These activities were generally available in both training and residential settings. In general, many more activities were available than were participated in by the patients (Table V).

COMMUNITY PROGRAMS AND SERVICES

The availability of various medical, educational and community programs varied from region to region. However, most regions appeared to provide equivalent and accessible services. Participation in the available services varied greatly from patient to patient, but in general, clients tended to utilize little other than various nursing, medical, dentistry, and therapy services.

TABLE IN SUMMARY OF DESCRIPTIVE CHARACTERISTICS OF CLIENT RESIDENTIAL SETTINGS

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TABLE V RESIDENCE PROGRAM ACTIVITY EVENTS

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Service specialities (physical therapy and speech pathology) were generally more readily available in larger communities (Table VI).

RESIDENTIAL SUPERVISION

Data on the residence client supervisors revealed that most (58%) of the supervisors possessed B.S. or B.A. degrees. Twenty-six percent were licensed practical nurses and thirteen percent had some college education, but no degree. One supervisor had less than a high school diploma. Thirty-six percent of the supervisors had no training specific to working with patients who have mental or emotional problems. Those with training (64%) had received their training via workshops and in-service.

Eighty percent of the residential supervisors had prior experience with supervisory work, although only two had worked previously with handicapped patients. Fifty-eight percent of the supervisors had worked at their current job for one year or less. Seven percent had 1 - 2 years experience, sixteen percent had 2 - 4 years of experience and nineteen percent had 4 - 6 years (Table VII).

IN-RESIDENCE TRAINING

The in-residence training programs available and utilized by clients were largely restricted to the types of training generally associated with nursing care type facilities (e.g., bowel and bladder training) and client involvement was voluntary in nature. Training and training supervision was provided by the same personnel responsible for general patient supervision, although several programs did have "actual directors" as part of their staffing patterns.

Nursing home facilities saw their role as providing physical care, personal comfort, attention and other assistance directed toward client happiness rather

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TABLE VII RESIDENCE CLIENT SUPERVISOR DATA

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*(Number of Supervisors Interviewed)
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than that of providing skill development and training. Group home programs tended not to conduct in-house training, but relied upon training resources and programs outside the home for services to the client.

HABILITATION PLANS

Individual habilitation plans within the residential settings were generally not in evidence and specific written training programs (goals and objectives) for individual clients were the exception rather than the rule. In nursing homes, charts and records were found to be the closest approximation to written training programs. In essence, there were no written treatment plans for emotionally disturbed patients who resided in any of the residential settings.

In summary, the in-residence on-site observations and information revealed that most patients were able to dress and feed themselves. Supervisory requirements varied greatly but most (73%) required either extensive or moderate supervision. Most patients had little access to or participated minimally in in-residence training programs. Generally, the larger the community, the greater the number of services, training programs and activities available to patients. However, even when programs were available, patients tended to participate only in medical, dentistry and related program areas.

Patient living conditions, care, clothing and personal privileges appeared to be duly considered within the majority of residential programs. However, limits were set for most clients for quantities and types of possessions, and for the opportunity to earn money. Most clients received a variety of financial support from state and federal programs and required assistance in managing their financial affairs. Access to medical, nursing and dental services appeared adequate to patient needs.

In general, individual habilitation plans were not found to be in evidence within the residential programs and the majority of residential programs had no written individual training programs for patients. The only written plans identified were found in group home placements. Generally, the residential programs viewed their responsibility as providing physical care, personal comfort and enjoyment activities rather than providing training related to skill development.

Two patients were identified in residence who did not have written Individual Habilitation Plans. Both resided in group homes. One of these patients had been transferred to the responsibility of the Developmental Disabilities Division and the other was enrolled in a Mental Health Center Program.

The majority of patients are under the direct supervisory responsibility of an assigned person. In most cases this would be a licensed practical nurse or a registered nurse. Most supervisors have had little prior experience or training in preparation for working with mentally handicapped patients.

PATIENT INTERVIEW DATA

All of those patients able to participate in a personal interview and determined to be sufficiently functional to respond to the interview questions were asked to participate. This status was determined by information contained in patient files and feedback obtained from on-site staff. Sixteen of the sample patients (36%) were so identified.

The information obtained from these interviews is presented in two parts in this section of the report. Part One, Table 8, presents a profile of the patients interviewed and includes information related to patients' age, sex, marital status,

TABLE VIII PROFILE OF CLIENTS INTERVIEWED

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education and current residence. Part Two contains a summary of the impressions and responses obtained from patients on various interview questions. This constituted client awareness of personal data (name, age, marital status and address), knowledge of personal affairs, awareness of treatment and therapy, medication, current condition, placement, professional contacts and satisfaction with placement. These questions were developed to obtain a picture of patient orientation, awareness of current and personal events and patient awareness of treatment and care, past and present.

In reading the accompanying narrative, the reader must keep in mind that
the patient-derived data was necessarily recorded and then summarized by the
investigators and that individual patients varied greatly in terms of their verbal
ability, reality awareness, medication levels and ability to relate to others.
All previously had been determined to be capable of at least limited interview
participation.

PROFILE of PATIENTS INTERVIEWED

A total of sixteen patients, nine males and seven females, were interviewed. Fifty percent were in the 56-75 age range, twenty-five percent fell between ages forty-four and fifty-five, and twenty-five percent were over 75 years of age. Eleven were single and five divorced. Twelve (75%) of the patients interviewed had an 0 - 8 grade education, three had 9 - 12 years of education and one had one year of higher education. Of the patients interviewed, eleven (69%) resided in nursing homes, three were in group homes, and one each were in a foster home or semi-independent living situation (Table IX).

CLIENT INTERVIEW SUMMARY

Seventy-five percent of the clients interviewed knew and could report accurate personal data about themselves (age, name, marital status and address). Sixty-three percent were knowledgeable regarding their financial affairs and responsible parties. Only one patient could describe treatment/therapy received while at WSSH, but ten (63%) had some knowledge of a treatment plan and individual involvement in treatment planning prior to exiting WSSH. Fifty percent (8) were able to give the approximate date of their exit from WSSH and fifty percent (8) could not give an approximate date of exit.

Although every patient reported knowledge of receiving medication(s) while at WSSH, and fourteen knew who administered the medication, only three were able to identify the actual medication they had received. Six patients (37%) were able to identify the medication(s) they were currently receiving, ten were unable. Fourteen of the interviewees (88%) were able to describe the type and frequency of currently administered therapy(ies). In addition, eighty-one

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TABLE IX - CLIENT INTERVIEW SUMMARY IMPRESSIONS

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percent (13) could give an accurate description of his/her daily routine.

When proced in terms of knowledge of condition or specific diagnosis, none of the patients were able to accurately identify their own. Four patients indicated awareness of their case manager and the remainder (10) were unaware or unsure (2) of who it might be. However, ten patients (63%) indicated awareness and involvement in developing a treatment plan with various Mental Health Center personnel.

Sixty-three percent of the patients interviewed indicated satisfaction regarding their current placement. Six would have preferred another placement or residence. The majority of patients (12) reported no specific problems, personal or otherwise; however, three would have preferred more activities.

In summary, patients knew little of specific medication, medical diagnoses of their problems, case managers and post-treatment or therapy at WSSH. A majority of the patients interviewed had accurate awareness of personal data, financial status, medication treatment, past and present, ongoing therapy, and daily routines. The majority appeared satisfied with their current placement and treatment, were aware of Mental Health services and treatment plans and had few complaints regarding specific problems, personal or otherwise.

IV. CLIENT DAY TRAINING PROGRAMS

PART IV

CLIENT DAY TRAINING PROGRAM ACTIVITY

This section of the narrative was designed to provide information about those patients who were involved in a specific training program (day training) outside their residential setting and to provide the reader with information regarding that training and the degree to which the patient was involved. A total of ten patients were identified as day training program participants.

All of these patients were toilet trained, ambulatory and capable of feeding themselves. One required assistance in dressing. Seven were viewed as requiring moderate supervision. (Table X)

The type of day training program, its location and specific content depended upon the individual client, location of residence and size of community. Seven of the clients were involved in day care activities with one each concurrently involved in an educational program, a sheltered workshop and an activity center/avocational center. The number of trainees and assistant trainers involved depended on the program and client count. Seventy percent of the clients involved had four or more training personnel available. The majority of the training programs provided moderate supervision as required by individual clients. The total number of persons involved in a training program, including target clients ranged in group size as follows:

- 1. 10 20, N=4
- 2. 20 40, N=5
- 3. 40 + N = 0
- 4. Insufficient data, N=1

TABLE X GENERAL DEMOGRAPHIC SUMMARY, FOR SURVEY TARGET POPULATION IN DAY-TRAINING PROGRAMS (N=10)

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Region III - 1 person involved jointly in Day Treatment & Sheltered Workshop

Length of involvement in individual training programs varied with clients, nine of ten having been involved for 1 - 3 years. Information collected from training personnel indicated that two patients were regarded as short-term, two were undetermined and six were long-term candidates for the training program. Training programs received their support funding from state, agencies, mental health centers, and private sources, singly or in combination.

Individual client (N=10) involvement in all types of "training" programs was summarized as follows:

- 1. One person was involved in an educational program on a regular half-day or less basis without pay.
- 2. Another patient attended a sheltered workshop 3 4 hours daily with pay on-a-piece production rate basis.
- 3. Two patients were involved in activity center programs 3 4 hours daily -- one was paid and the other was not.
- 4. Six individuals were participating in a variety of day-care training programs (arts and crafts, cooking, shopping, etc.) and in all cases for 3 4 hours daily or less.

Note: none of the day care training programs paid clients or provided for paid work experiences.

Written comprehensive training programs for individual patients were in evidence for five (50%) of the patients and for five no written programs were available. The five written programs contained specific outcome goals and specific goal related objectives for each client. For the five clients without written programs, it was impossible for the study team to discern specific client goals, objectives, progress or direction.

PATIENT TRAINING SUPERVISOR DATA

The educational background of the clients' designated supervisors ranged from less than a high school diploma (N=1) to a Master's degree (N=1). Most of the training supervision was provided by licensed practical nurses (10%) or registered nurses (40%). Training supervisors reported received their own training for working with these patients via in-service and in-program workshops. However, forty percent of the training supervisors had no specific prior training nor had they received any in-service or workshop training specific to working with this previously institutionalized population.

Six of the training supervisors (60%) had held their current position for one year or less. Two had been on the job for 1 - 2 years, one for between 2 and 4 years and one for more than four years. (Table XI)

TRAINING in SHOPPING, LEISURE TIME and TRANSPORTATION SKILLS

Patient training in shopping, leisure time and safety skills were an integral part of several training programs. Patient participation in a given skill area was determined by patient willingness to participate, by training program appropriateness (determined by training staff) and by resource availability. (Table XII)

Shopping skills were being taught to two patients, recreation and leisure skills to two patients and three were being taught safety skills. In general, transportation utilization skills were not taught in any of the training programs. However, orientation and direction finding were a part of the program for four clients. One client was receiving training in the use of

TABLE_XI SUMMARY OF TRAINING SUPERVISOR'S EDUCATION, TRAINING & EXPERIENCE

NUMBER OF YEARS IN CURRENT JOB POSITION A. 6 mo. or less B. 6 mo. to 1 yr. C. 1 - 2 yrs. D. 2 - 4 yrs. E. 4 - 6 yrs.	A. None B. Workshops & Inservice PRIOR WORK EXPERIENCE RELATED TO CLIENTS (Area/Service/Training) A. Previous Job Experience B. Relative Handicapped	EDUCATION (Highest level attained) A. Less than High School Diploma B. High School Diploma LPN C. 1 - 3 yrs. college: not completed D. B.S. or B.A. degree R.N. F. H.S. or M.A. Degree TRAINING SPECIFIC TO CURRENT PROGRAM		
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public services (fire, police and library programs). None of the clients were receiving training in budgeting or finance management skills.

In addition to specific training programs, most training sites offered a wide variety of personal and/or leisure related activities. Field trips, movies, celebrations, records, radio listening, arts and crafts, walking, gardening, parties, reading and many more comprised the total spectrum of regular and occasional events. (Table XIII)

The major means of transportation for most clients (7) was walking with six of the clients being transported by car or van on a regular or occasional basis. (Table XIV)

Training staff felt that eight of the ten clients had been completely and successfully integrated into their respective communities. Integration was considered partial for two patients. Problems related to re-integration efforts were found to center around the need for re-education of the public (N=8), problems related to medication (N=2), lack of suitable available housing (N=1), and poor client social skills (N=1). (Table XV)

Problems related to providing client training appeared to center around insufficient funding (N=2), public acceptance N=2), client abilities (N=1), lack of client progress (N=2) and staffing/communication problems internally (N=4). (Table XV).

When the ten training supervisors at each training site were asked if their programs could accommodate (ability and/or capacity) increased numbers of "high risk" patients like those being surveyed, six reported they could not and four reported they could accommodate additional clients.

Plane Rido, Circus, Puzzles, Walks, Drives, Vacations, Wrestling, Church, Games (Table), Cards, Shopping, Horseshoes, Beauty classes,	OtherIncludes:	- 1	Boating	Fishing	Motorcycle Riding	I	Ice Skating		Celebration of Holidays and Birth-	P.E. Activities	Arts & Crafts	Strimmingi	Parties	Model_Building	Reading	Woodworking	sewing	Cooking	Bicycling	Bowling	Gardening	Camping/Hiking	Nusic	Records, Radio	Dances	Sports Events	Telcvision	Novies	Field Trips			5 TABLE XIII	0
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wa ware In summation, client day training programs provide alternatives for ten patients, or twenty-two percent of the target group. Presence of toilet training, ambulation, self-feeding and dressing skills characterize this group.

Day training programs vary greatly in programmatic structure and staffing and are determined within each region by community size, patient needs and available resources. Day training programs tend to be supervised by assigned persons identified for that purpose. Most clients require moderate supervision. The length of client participation in the programs tends to be long-term; 9 of 10 clients with 1 - 3 years, and with all clients participating on a half-day or less basis. Five of the clients had written comprehensive training programs containing goals and objectives. The other five had no written programs.

The training given training supervisors appeared most commonly to be on-the-job, in-service and in-house provided workshops. The majority of training supervisors (63%) had been in their positions for one year or less.

Most training programs were centered around shopping. leisure time and personal safety skills. Financial and budgeting skills were not a part of this programming. Most training programs integrated a wide variety of leisure time activities (walking, music, field trips, etc.) into their training programs.

Training supervisors perceived most clients to be successfully integrated into the community setting, but also identified public acceptance and medication problems of clients as integration related problems. Sixty percent of the training programs expressed concerns regarding their ability to serve more and/or higher risk clientele.

V. THE ADAPTIVE BEHAVIOR SCALE

PART V

THE ADAPTIVE BEHAVIOR SCALE

INTRODUCTION

The Adaptive Behavior Scale (ABS) was selected as the best of the available instruments to measure a deinstitutionalized patient's ability to adjust to his/her community placement. It is easily administered and scored and the data obtained from it will provide additional information to be incorporated in the entire study.

THE ABS DOMAINS

The domains included in part one of the ABS reflect the functional ability one needs to perform vocational tasks. They also measure a person's capability of doing work and caring for themselves in an independent living setting. Further, one's ability to handle money, tell time, communicate with others and function in a responsible manner is evaluated.

Information from the composite scores obtained in all of the domains gives an indication of whether a person is able to function independently and obtain and maintain a job necessary for self support.

The domains measured in part 2 provides data relative to a patient's interpersonal behaviors. They demonstrate whether an individual's behavior falls within norms acceptable in society. If a patient's personal behavior is abhorrent to those around him, the chances are not favorable to independent living or obtaining and maintaining employment that would lead to self sufficiency.

There are three difficulties in using this instrument even though it is the best available. The first problem lies with the normative group. The normative sample population was generated from institutionalized mentally retarded

persons and mentally ill persons. However, in reviewing recent literature relative to the use of this scale, the evaluators could not find other instances where it was used with the mentally ill. After observing the patients at WSSH during an on-site visit, they were found to be functioning on a very low level so a decision was made to use the ABS.

The second problem arose from the administrative of the scale. The scale is designed for easy administration by people who have little formal training in its use. Aides, parents, technicians and protective service workers who have knowledge about the patients' behavior can easily provide the necessary information. All one has to do is read the instructions provided in the test booklet, then go to the various domains and check responses or lack

of responses that most closely approximates the patients' functioning level. The verbal instructions given to those individuals who were to administer the scale were consistent throughout and if confusion arose, one merely had to refer to the instruction booklet. A problem arose, however, when some of the nursing home personnel were asked to complete the ABS. They refused on the grounds that it took too much of their time, it was revealing confidential information, or they didn't know how to use the scale and were unwilling to learn. It was necessary for the nursing home personnel to follow instructions provided with the tests. No additional learning was expected of them. This was particularily evident in a Billings Nursing Home. Consequently, only thirty-eight scales were returned for inclusion into the study.

The third problematic area is inherent in using a zero response generated by the scale. A zero response may place the sample group within the maladjusted range when in fact they do not exhibit abnormal behaviors. This is especially true in part two of the scale and it must be viewed with caution.

ADAPTIVE BEHAVIOR SCALE - PARTS ONE and TWO

Part One differs from Part Two in that a high score obtained in the first part indicates the patient has obtained the skills listed in that domain. A high score is a positive indication of a person's abilities and reflects favorably upon the individual. However, in Part Two, a high score would indicate the person has adapted less to societal expectancies. In fact, a score above the 80th percentile means the patient is exhibiting maladaptive behaviors which are unacceptable to society. A high score in this section is a negative indication of

a person's ability to adapt and is looked upon in a negative way.

RESULTS of the ABS

Part One - (Table XVI)

There are ten domains listed on the profile summary sheet. Each domain will be briefly discussed. If there is more importance placed upon an area of functional ability, it will be discussed in more detail.

Independent Functioning

The thirty-eight patients attained an average raw score of 53. This places them slightly above the tenth percentile. Included in this domain are body balance, ability to walk and run, control of hands and limb functioning.

Economic Activity

The patients scored slightly below the 40th percentile in this domain.

This score is one of the three highest scores attained in part one. Included in this area is a person's ability to handle money and budget what money they do have. Those people placed in nursing homes have little opportunity to use skills in this domain so they would be unable to use their abilities in a constructive, independent way.

Language Development

A score of 17 was obtained placing the group at the 22nd percentile. This score indicates that the patient expresses himself/herself poorly in verbal and written form. It also indicates communication difficulties.

Numbers and Time

This area samples a person's ability to add and subtract, to use the clock and to know the days of the week; or whether it is morning, afternoon or evening.

	TABLE XVI Identification	Composite	
	(Page 1 of 2)	50-69	
		both	
D.A.T.	Date of Administration A SUMMARY SHEET - AAMD ADAPTIVE BEHAVIOR SCALE	8-77	
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The raw score derived in this domain placed them in the 45th percentile.

The highest percentile rank reached by the sample was in this area.

Domestic Activity

This domain measures a person's ability to wash dishes, make beds and assist with routine homemaking activities. A raw score of four was derived placing the patients at the 35th percentile.

Vocational Activity

A raw score of one and a percentile rank of 29 was obtained in this domain.

The chances of a person with that raw score of engaging in gainful employment are low. When this domain is included with the others in Part One, it reaffirms the above statement.

Self Direction

This item measure a patient's initiative, passivity, attention and persistence.

The people in the sample accrued a raw score of seven. This placed them at the tenth percentile level.

Responsibility

The 39th percentile was attained by the sample in this domain. It measures a person's abilities to be responsible for his/her personal belongings, and his/her dependability or unreliability. A raw score of three was the average for the group in this particular area.

Socialization

Cooperation, consideration for others, awareness of others, interaction with others, selfishness and social maturity are the domains measured under this category. A raw score of seven was derived from the individuals in the sample. This places the group at the second percentile.

Part Two - Table XVII

This part of the ABS focuses upon personal characteristics which would cause a patient to be considered maladaptive. It contains fourteen domains and as in part one, specific problematic areas will be highlighted. While interpreting this data, the reader must be aware of the precautions discussed in the introduction to this section. A zero response indicates the patient does not exhibit the maladaptive behavior. However, when the zero response is placed on the percentile scale in some instances, it exceeds the 80th percentile and the behavior is, therefore, considered maladaptive. The evaluators attempted to contact the originators of the ABS to determine whether the data in Part Two could be presented in a different manner. We were unsuccessful in our attempts. So, not to compromise the information provided in this section, it will be presented according to the instructions provided in the test booklet.

Violent and Destructive Behavior

Items in this domain include: threatening or doing physical violence, damaging either personal or other's property, damaging public property or having a violent temper or temper tantrums. The people in the sample obtained an average score of two and this placed them at the 65th percentile rank. This score indicates the patients in the sample were not considered maladaptive.

Anti-social Behavior

Behavior focused upon in this domain are teasing, gossiping, bossiness, manipulation, showing disrespect toward other's property and using angry

TABLE XVII (Page 1 of 2)

DATA SUMMARY SHEET

PART TWO

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IV.	UNTRUSTWORTHY BEHAVIOR	0	IV
V.	WITHDRAWAL	5	V
VI.	STEREOTYPED BEHAVIOR AND ODD MANNERISMS	3	VI
VII.	INAPPROPRIATE INTERPERSONAL MANNERS	1	VII
V///.	UNACCEPTABLE VOCAL HABITS	1	VIII
IX.	UNACCEPTABLE OR ECCENTRIC HABITS	3	IX
Х.	SELF-ABUSIVE BEHAVIOR	0	X
XI.	HYPERACTIVE TENDERCIES	1	ΧI
ХП.	SEXUALLY ABERRANT BEHAVIOR	0	XII
XIII.	PSYCHOLOGICAL DISTURBANCES	14	XIII
XIV.	USE OF MEDICATIONS	1	XIV

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(Page 2 Of 2)	Identification Composite
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	Sexboth
Date	of Administration 8-77

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language. The patients accrued a raw score of two and that score placed them in the 65th percentile.

Rebellious Behavior

A raw score of three placed the sample at the 80th percentile. Behaviors included in this area include: ignoring regulations and routine, resistance to following instructions, a rebellious attitude toward authority, absence from or late for proper assignments or places, and running away.

Untrustworthy Behavior

Included in this category are behaviors such as taking property without permission, lying and cheating. The raw score for the individuals in the sample was zero and this placed them at the 50th percentile.

Withdrawal

The sample fell at the 85th percentile with an average raw score of 5.

This was one of the highest scores obtained in Part Two of the ABS. Behaviors recorded in this domain were inactivity, withdrawal and shyness.

Sterotyped Behavior and Odd Mannerisms

This domain focuses upon a peculiar posture or odd mannerisms. The patients' average raw score was three. This placed them at the 90th percentile.

Inappropriate Interpersonal Manners

Behaviors such as: talking too close to others' faces, blowing in others' faces, burping at others, kissing or licking others, hanging onto others, are included in this domain. The sample population derived an average raw score of one and was placed at the 85th percentile.

Unacceptable Vocal Habits

This domain includes behaviors such as giggling hysterically, talking too loudly or yelling, talking to self, growling, mimicking others and repeating phrases and words over and over again. The group obtained an average raw score of one and were placed at the 82nd percentile.

Unacceptable Eccentric Habits

The patients in the sample fell at the 85th percentile after having obtained an average raw score of three. The eccentric habits include removing or tearing of one clothing, drooling, grinding teeth, smelling everything, playing with feces and urine, and hoarding.

Self-Abusive Behavior

The behavior included in this category falls under a broad area of a person doing physical violence to himself/herself. However, the sub-domains incorporate actions such as biting or cutting oneself, slapping or striking oneself, banging one's head or parts of one's body against objects, pulling one's hair, scratching or picking oneself causing injury, poking objects in one's own eyes, ears, nose or mouth, and soiling oneself. The sample group falls at the 80th percentile and their raw score is zero.

Hyperactive Tendencies

The average raw score from the patients examined was one. This placed the entire group at the 90th percentile giving it the highese percentile rank in Part Two of the scale. Hyperactive tendencies include talking excessively, the inability to sit still for any length of time, constant running and jumping around a room or a hall, and constant moving and fidgeting.

Sexually Aberrant Behavior

The sample fell on the 80th percentile level. They generated an average raw score of zero. Approximately five individuals scored higher than zero. This aberrant behavior includes inappropriate masturbation, exposing one's body inappropriately, having homosexual tendencies, and exhibiting sexual behavior that is socially unacceptable.

Psychological Disturbances

Oddly enough this sample group scores at the 75th percentile placing them below what is considered maladaptive. The raw score for the patients was four and behaviors included in this category are an over-estimation of abilities, an inappropriate reaction to criticism, feelings of persecution, hypochondrial tendencies and emotional instability.

SUMMARY and CONCLUSIONS of the ABS

The major conclusions drawn from the data provided by the use of the ABS are:

- 1. The patients involved in this study cannot live in a totally independent living situation.
- 2. Their behavioral manifestations fall within the maladjusted range in most areas.

Part One of the profile measures skills possessed by the patient.

Independent living, physical development, self-direction and socialization are skills of which the patients have few. They fall below the 15th percentile in all of those areas. Those in the sample population fall below the 40th percentile in economic activity, language development, domestic activity, vocational activity and responsibility. In only one skill area does this group of people exceed the 40th percentile and this is the ability to work with numbers and time. They reach the 45th percentile in their capability of using those skills. The data indicated that the patients do need constant supervision because of their inability to care for themselves in their everyday activities.

Part Two of the ABS provides data relative to the psychosocial aspects of an individual's behavior. As was previously expressed in the introduction to the section on the ABS, caution must be used in drawing conclusions from this information.

The data does show the patients to be withdrawn, rebellious, stereotyped in their behavior, using inappropriate mannerisms, hyperactive, exceentric and self-abusive. They do not exhibit excessive violent and destructive behavior, anti-social behavior and untrustworthy behavior. Nor do they fall within the maladaptive range in psychological disturbances. That statement seems contradictory to the basic premise of this study but the data indicates otherwise.

VI. SUMMARY AND CONCLUSIONS

PART VI

SUMMARY and CONCLUSIONS

The followup survey of deinstitutionalized and mentally ill or emotionally disturbed patients/clients included an initial target population sample numbering sixty. Community placed patients were randomly selected from the WSSH files by region to assure a state-wide sample. The sixty were reduced to fifty-eight after one was found to be deceased and another to have moved from the state. An additional thirteen members of the target group were lost for varying reasons, as discussed in another section of the report. Thus, forty-five persons comprised the total survey sample. However, four clients had no Mental Health Center files and were excluded from that phase of the study.

The information and data collected during the followup study was obtained in the following fashion:

Initial Visits

Initial visits were made to WSSH to thoroughly examine individual patient files pulled at random by WSSH staff according to the instructions provided by the evaluators. This provided familiarity regarding the nature and content of the files. WSSH staff were extremely cooperative in providing whatever assistance we requested.

Computer Printout of Patients

Next, a computer printout of all patients having exited WSSH since 1970 was obtained. Having determined that the target sample was to include only patients having exited after a minimum of three years of hospitalization, we randomly selected our target pool. The WSSH files for the target group were

thoroughly examined and the necessary data extracted.

Followup

Followup of each patient was commenced by locating the Mental Health Region and Center to which the exited patient was assigned. Several shifts were identified and various patients were found to be deceased, to have moved or to have become "lost" in terms of record keeping. Individual Mental Health Centers were visited and each client file examined and data extracted. These reviews included treatment, medication, contracts, case management, etc.

Clients Located and Visited

Next, each client was located in terms of current residence and each site was visited by the survey team. The survey team conducted a site survey, client interviews (where possible), supervisor interviews, file and record reviews, observed training programs and contacted other available site personnel. Data collection using the Adaptive Behavior Scale was also arranged. Finally, where appropriate, training programs outside the residential setting were also visited and training data was collected.

Data Collection

The survey team attempted to collect a comprehensive set of data reflectively, quantitatively and qualitatively on all aspects of patient activity and involvement following exit from WSSH. The data collection forms for each area are presented in the Appendix. The narrative findings for each section/area have been presented earlier within the respective sections of the report.

CONCLUSIONS

The following conclusions regarding the survey data and information collected are those of the survey team and reflect the team's understanding and interpretation of the objectives established for the survey, and should not be interpreted as reflecting any one else's conclusions.

The age of the target group ranged from a low of 22 years to a high of 95 years, with a group mean age of 65.6 years. Twenty-nine of the group were male and twenty-nine were female. Thirty-one percent of the group had received standard commitment and thirty-eight percent were voluntarily committed. Thirty-one percent of the patients had been committed during the 1960's. For seventy-one percent of the group this commitment was their initial or only commitment. Twenty-seven different diagnostic categories were assigned to patients as their primary diagnosis at time of commitment. Hallucinations, delusions, disorientation and violence chaaracterized patient behaviors at time of commitment.

Upon release, the majority of patients were returned to the region of their original homesite. Most patients (75%) were found to have been placed in nursing homes in or adjacent to their home towns. At the time of release from WSSH, the length of time a patient had been hospitalized ranged from three to fifty-three years. The mean length of stay for all clients in the sample was 19.93 years. Twenty patients (49%) had spent 30 or more years at WSSH.

Mental Health Center files were reviewed to obtain individual client data following release and placement in their respective mental health regions.

File reviews were conducted on forty-one patients. This data appeared

consistent with patient data derived from the WSSH files. Mental Health

Center files varied considerably in terms of nature and content. In general,
the files contained information regarding the patients' privacy, diagnosis,
current residence, case manager, treatment logs, identified problem areas,
additional diagnostic information, medical data, and contact schedules. The
extent of this information varied from minimal to extensive. Only limited data
was available regarding communications and followup between WSSH and the
Mental Health Centers.

The study of in-residence patient status indicated that of the forty-five patients, over eighty percent were toilet trained and ambulatory and a majority were able to dress and feed themselves. Supervisory arrangements identified seventy-three percent of the patients as requiring either constant or moderate supervision. There was very little evidence, if any, of in-residence training or training provisions for this population; however, some patients were involved in training programs located outside the actual residence itself. The availability of community based training programs was in general related to community size. Fifty-eight percent of the clients were located in communities with a population of 10,000 or greater.

Most residential programs (84%) were directly involved with some type of advisory board. In most settings, there were restrictions and limitations placed upon client possessions, client opportunity to earn money and client management of own funds. Fifty percent of the patients had ready access to telephones for incoming and outgoing calls. Most settings provided a wide range of leisure or recreational activities and viewed the major portion of their

responsibility to be that of making patients comfortable, providing physical care and assistance and facilitating pleasure or leisure time opportunities. Patient participation in various programs was largely voluntary. Service specialities (therapy, speech, medical and dental services) were generally available and utilized on an as-needed basis.

Residential supervision was adequage. However, most supervisors lacked training specific to the handicapped population and had held their jobs for one year or less. Most supervisory personnel were drawn from the staff of licensed practical or registered nurses at the facilities reviewed.

Ten patients (22%) were found to be involved in day training programs outside their respective residental settings. Most of these people were participating in day care activities. Others were involved in educational, sheltered workshop and avocational center programs. Training was viewed as long-term (1 - 3 years) and centered around shopping, leisure, safety, community service, self care and recreation type activities. Training supervision was usually on a group basis and was provided by licensed practical nurses or registered nurses. Training of supervisors was, in general, not specific to this type of population. In-service programs and workshops were the major means of preparing training supervisors.

In general, the training personnel felt that the majority of clients (80%) had been completely and successfully integrated into their community.

Integration related problems were identified as the need for public awareness and education, client/patient medication problems and client skills. Training problems tended to be centered around funding, client participation, client progress and staffing/communication problems. Training program personnel

were extremely cautious regarding their ability to serve more patients and particulary hesitant about their capacity to serve more "high" risk patients.

All patients able to participate in a personal interview were interviewed.

Sixteen patients (36%) were so identified. Most of the patients were found to possess accurate personal information regarding their name, age, marital status and address. Patients were aware but not specifically knowledgeable regarding past and present treatment or medications. Patients had little understanding of Mental Health Centers or residence services, and none knew their own specific diagnosis; however, they were aware of all these areas and their own involvement.

Sixty-three percent indicated satisfaction with their current placement, while six patients indicated a preference to be elsewhere. The majority (75%) reported no serious personal problems or concerns and felt that they were being adequately cared for and treated appropriately.

The Adaptive Behavior Scale was selected as the best available tool to attempt to measure the patient's ability to adjust to their community placement following deinstitutionalization. The study team encountered three major proglems in using this instrument:

- 1. The norm group was primarily institutionalized retarded.
- 2. Refusal of the nursing home staff (nurses in particular) to cooperate in completing the ABS. (The scale is significantly more useful if filled out by individuals personally knowledgeable about their patient.)
- 3. The scoring procedure which places zero responses into the maladjusted range tends to distort the data and data analysis.

The major conclusions drawn from the data provided by the ABS were:

- 1. The patients involved in the study could not live in a totally independent living situation.
- 2. Their behavioral manifestations collectively fall well within the maladjusted range in most cases according to the test results. However, most of the people tested did not exhibit maladjusted behaviors and the negative results come from the test design.

RECOMMENDATIONS

The following recommendations are presented within a general summary statement format and are intended to familiarize the reader with the major issues or concerns identified by the survey team members during their work across the several regions.

Each of the following recommendations was based upon a composite of information data drawn from:

- 1. The material presented within each of the major sections of the report (Review of Mental Health Center files, Patient Residential Data, Client Day Training Programs, Client Interviews, Case Manager Interviews, Adaptive Behavior Scale, etc.).
- 2. The descriptive narrative, for each major part of the report and the summary sub-sections of each part.
- 3. Survey team logs, report and report notations recorded during on-site visits, interviews and other data collection activities.

It is recommended that:

In the future, all transfers from WSSH to regional placements occur only after the selected placement sites have been adequately oriented and prepared for the reception of transferred patients. This would alleviate most of the problems cited by residential personnel which included lack of familiarity with that "type" of patient, several patients arriving at the residential site without our prior knowledge and assigning non-ambulatory patients to facilities without the resources to provide for patient movement and transportation.

- 2. In all cases, active case managers should be maintained for each client and that the assigned manager maintain an active and planned followup procedure for each client. Also that the duties of the case manager be more clearly delineated and articulated to all the parties involved. Patient placement without assignment to a case manager; case managers without knowledge and understanding of assignment; frequent staff turnovers, case management as a secondary role; and contracted disputes between providers and mental health were all seen as contributing factors to the case manager issue.
- 3. Serious consideration be given to the possibility that for many patients deinstitutionalization has been no more than a process of movement from one setting to another, and that in actuality there is little evidence of any concerted effort to provide training or assistance to the patient to facilitate normalization on re-entry into the community on a functional basis.

The nursing home operators who provided for the majority of patients included in the survey, defend their own role as providing shelter, food, clothing and patient care. The majority did not view training, community integration and patient skill development as a part of their responsibility. Most were not equipped, staffed or programmetically oriented to delivery other than basic personal health care services.

4. Serious consideration be given to the development of a planned procedure for the active followup of all patients as they are transferred from WSSH to another placement site. It is further suggested that this followup procedure remain "active" for at least one full year following transfer.

The placement information derived from the study reflected several instances of patient exit from WSSH without corresponding patient receipt action on the part of the designated Mental Health Center. Patients were transferred out of state and to other sites without adequate information regarding the patients' new location, reason for transfer, etc.

5. A procedure be established to upgrade the record keeping and file systems responsible for tracking each patient in and out of WSSH. Many patient files are outdated, incomplete or even missing. A better tracking system for patients themselves appears needed as several patients appeared to have disappeared after transfer from WSSH.

The patient files vary markedly from location to location and there appears to be little inter-agency consistency in record keeping procedures and file content. In the residential settings there is highly variable evidence of data collection on patient progress, patient evaluation, and patient training. 6. Minimal standards be established for the training and supervision of "key" personnel who are assigned the primary responsibility for the treatment and training of deinstitutionalized patients.

Currently assigned supervisors tend to be new to the job (less than a year); lack professional preparation or training specific to the needs of the studied population; and have little access to additional training other than on-the-job.

7. Specific criteria be established for those sites under consideration for the placement of deinstitutionalized patients, and that said sites be evaluated in terms of their capacity to provide care, treatment and training commensurate with the identified goals and objectives for each patient.

Currently, patient placement is determined largely by regional placement and site availability with a particular region. There was no evidence of planned attempts to match patient needs with specific site, treatment programs, or training program availability.

8. Each residence and training site have on-hand a written plan(s) reflecting the care, treatment and training goals and objectives for each of its deinstitutionalized patients.

Written plans, particular active treatment plans reflecting specific goals and objectives, for individual patients were common only to the Mental Health Centers. Residential placements rarely worked from a written plan. The commonly noted residential records were the daily medical/nursing logs kept on individual patients.

9. Efforts and procedures be established to monitor and assess patient progress in their various placement sites in terms of progress toward increased normalization.

The Mental Health Centers and residential programs, in general, did little to monitor and assess patient progress in terms of any specific progress toward increased normalization. The pervasive view was that the patients current placement was terminal.

10. A closer liason be established and maintained between the Mental Health Centers, satellite programs and patient placement sites.

Mental Health Centers tend to be most extensively involved in the programs they operate and cooperatively administer. However, communications between several of the Centers and their own satellite programs reflected a need for improvement. More liason, direct support and visitation are among the needs identified. Liason between Mental Health Centers and private residential placement sites varied greatly with most being described as marginal.

APPENDIX A

WSSH CLIENT FILE DATA FORM

.

APPENDIX A WSSH CLIENT FILE DATA FORM

CASE NUMBER:	
- NAME:	
ACE:	
SEX:	· —
MARITAL STATUS:	
FAMILY MEMBERS:	
·TYPE-COMMITMENT:	:
REASON-HOSPITAL:	
OCCUPATION:	
DATE-HOSPITAL:	
PREVIOUS-HOSPITA	L:
· IN:	
OUT:	
In:	
OUT:	
(DO NOT USE)	<u>1</u>
. In:	
OUT:	
In:	
OUT:	
PRIMARY DIAG.:	
ECONDARY DIAG.:	
EDICATION-ADM.:	
TREATHEMT-WSSH:	
ATE-RELEASE:	
EGION-RELEASE:	

DIAGRELEASE:	program brissian believes process groups
MEDICATION-RELE.:	
TREATMENT PLAN:	
LOCATION-RELEASE:	potential.
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APPENDIX B

RAW DEMOGRAPHIC CLIENT PROFILE DATA FROM WSSH FILES

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RAW DEMOGRAPHIC CLIENT PROFILE DATA FROM WSSH FILES

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RAW DEMOGRAPHED CUIENT PROFILE DATA FROM WISH FILES

	DATA CATEGORIES	N	%	DATA CATEGORIES	3.5	%,
11.	SECONDARY DEAGNOS (S:			13. RELEASE-REGION:		
	300.0	3	5.17	Region No. 1	9	15.51
	300.1	1	1.72	Region No. 2	9	15.51
1	300.2	2	3.44	Region No. 3	15	25.86
	300.3		12.06	Region No. 4	15	25.86
	300.6	1	1.72	Region No. 5	10	17.24
1	300.7	13	22.41		58	100.00
	301.1	3	5.17	14. RELEASE-LOCATION/CITY		
	303.0	1	1.72	Billings	9	15,52
1	304.0	-		Helena	4	6.90
	306.0	2	3.44	Glasgow	2	3.44
	308.1	1	1.72	Butte	12	20.69
	309.2	1	1.72	Missoula	2	3.44
	320.0	1	1.72	Sheridan, Wyo. (VA) (1)	NA	NA
	320.1	1	1.72	Miles City	1	1.72
	321.1	1	1.72	Dillon	1 '	1.72
	322.1	1	1.72	Harlem	2	3.44
	324.2	-		Conrad	1 .	1.72
	325.1	1	1.72	White Sulphur Springs	1	1.72
	325.2	1	1.72	Havre	. 1	1.72
	325.3	5	8.62	Hot Springs	2	3.44
	328.4	4	6.89	Clancy	1	1.72
	328,5	2	3.44	Galen	2	3.44
	328.7	1	1.72	Superior	1	1.72
	328.9	2	3.44	Great Falls	2	3.44
	353.9	2	3.44	Whitefish	3	5,17
}	794. 9	1	1.72	Big Timber	1	1.72
	025.6	. 2	3.44	Stevensville	1	1.72
Ĺ		58 I	.00.00	Lewistown	3	5.17
12.	DATE OF CLIENT REL	EASE		Livingston	3	5.17
	1-72	1	1.72	Blackfoot Nursing Home	1	1.72
	8-72	1	1.72	Unknown	2	3.44
1	3-74	1	1.72		58	100.00
	6-74	1	1.72	15. PRIMARY MEDICATIONS	N	N
	12-74	1	1.72	}	Admiss.	At Release
'	2-75	1	1.72	1. Artane	2.	1.0
}	3-75	1	1.72	2. Senetel	1	2
	7-75	4	6.89	3. Salfutensin	0	1
1	9-75	1	1.72	4. Mygdic	0	4
	10-75	1	1.72	5. Vitamin C	1	8
	1-76	2	3.44	6. Sulfax	0	1
	3-76	1	1.72	7. Stelazine	3 5	10
	7∸76	22	37.93	8. Thorazine	5	8
	8-76	2	3.44	9. Bercocco	0	2
	9-76	2	3.44	10. Millaril	1	9
	10-76	7	12.07	11. Serentil	1	6
	11-76	2	3.44	12. Ascorbiv Acid	0	0
	12-76	2	3.44	13. Dilantin	3	6
	1-77	2.	3.44	14. Bactrim	0	1
	2-77	2	3.44	15. Bentyl .	0].
				lt. Tofranil	0	2
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RAW DEMOGRAPHIC CLIENT PROFILE DATA FROM WSSH FILES

	DATA CATEGORIES	N	%	DAT	TA CATECORIES N %	
15.	PRIMARY MEDICATION	S. Cont'd.		15.	PRIMARY MEDICATIONS, Cont.	7
	Titling Transfer	N	N	13.	N	N
	A	t. Admiss	At Release			1 At Release
18.	Albee	0	1	63.	Multivitamins 0	2
19.	Haloperidol	0	1	64.	Equanil 0	0
20.	Vasodilan	0	2	65.	Thromine 0	1
21.	Trilafon	0		66.	Marax 0	0
22.	Hydergine	1	7	67.		0
23.	Reserpine	0	î	68.		1
24. 25.	Luminol Vistaril	1	î	69.	Kemadrin 0	0
26.	Lineguan	Ô	î	1 1	General Protein 0	1
27.	Beracl1	0	ĩ	72.	Theragam M 0 Ritalin 0	-1
28.	Prolixin Decanoate	o l	4	73.		1 '
	NPH Insulin	0	0		Staril 1	0
30.	Pyridene	0	1	7	N= 33	56
31.	INH	0	0	-	11- 33	. 50
32.	Tederal	0	1	16.	TREATMENT DURING HOSPITAL:	N
33.	Surfok	0	3		Chemotherapy	33
34.	Metamucil	0	1		Socialization Arrangement	1
35.	Hydergin	0	0		Work Therapy	1
36.	Haldol	0	2		Occupational Therapy	4
37.	Aminophyllin	Ţ	1 2		Custodial Care	9 .
38.	Sparine	0	4		Milicu Therapy	27
39.	Protamine Zine		1		Group Therapy	5
40.	Insulin Incremin	0	1		Daily Living Activities	4
41.	Valium	0	o l	}	Recreational Therapy Medical Treatment	4
42.	Spansules	0	0		Supportive Counseling	2 9
43.	Lomaxin	o l	1	İ	None	7
44.	Arlidin	o l	2		Electroshock Therapy	10
45.	Narose	0	1		Individual Psychotherapy	1
46.	Pavolrid	0	3		za, and zapy	
47.	Moldane	0	1	17.	TREATMENT PLAN FOR RELEASE	N
48.	Fertal	0	1		Chemotherapy	14
49.	Cogentin	0	2		Structured Living	3
50.	Peritrate	0	1		Socialization Arr.	4
51.		38	2 0	}	Nursing Home	13
52.	Unknown	1	0		Rest/Convalescent Nome	20
53.	Several Unknown	1 0	1		Occupational Therapy	2
54. 55.	Insulin Phenobarbital	2	5		Custodial Care	2
56.	None	5	1		Milicu Therapy	6
57.	Mineral Oil	0	0		Sheltered Workshop Recreational Therapy	2
58.	Mysodine	1	0		Croup Home	2
59.	Doridine	1	0		Day Care Treatment	1
60.	Paladac	0	2		Attend School	1
61.	Ducolax	1	0		Supportive Counseling	<i>l</i> ,
62.	Hygrotan	0	2		None,	i
					Mental Health Center	1
					Family Care	1
			1	H	Transfer to Galen	2

RAW DEMOGRAPHIC CLIENT PROFILE DATA FROM WSSH FILES

	DATA CATEGORIES	- 2°	%	DATA CATEGORIES	N	7
18.	HOSPITALIZATION - REASO	Ά		19. HOSPITALIZATION - LEN	CTH OF	STAY
	Hallucinations	_ 7	12.06		N	7,
	Delusions	6	10.34	0 - 2 years	1	1.72
	Depression	3	5.17	3 - 5 years	11	18.97
	Disorientation	6	10.34	6 -10 years	10	17.24
	Violence	5	8.62	11 -15 years	10	17.24
	Feeblemindedness	2	3.44	16 -20 years	3	5.17
	Paranoia	1	1.72	21 -25 years	0	
	Alcoholism	4	6.89	26 -30 years	3	5.17
	Beligerency	1	1.72	31 -35 years	4	6.90
	Drug Addiction	2	3.44	36 -40 years ·	2	3.44
	Declared Incompetence	2	3.44	41 -45 years	5	8.62
	Senility	2	3.44	46 -50 years	5	8.62
	Unable to Care for self	6	10.34	51 -55 years	2	3.44
	Suicidal	3	5.17	Unknown	2	3.44
	Runaway	1	1.72		58	100.00
	Bizarre Behavior	2	3.44			
	None Listed	1	1.72	Range 2 - 53 years		
	Epileptic Seizures	2	3.44	Mean = 19.93 years		
	Transfer from BRS & H	1	1.72	Median = 13 years		
	Family Burden	1	1.72	Mode = 7 years		
		58	100.00			

APPENDIX C

INDIVIDUAL CLIENT DATA: MENTAL HEALTH CENTER FILES

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INDIVIDUAL CLIENT DATA: MENTAL HEALTH CENTER FILES

r ner	Follow-up Client Number	er of of	
	RSONAL CLIEDT DATA:	W. 6	
	W.S.S.H. Case No.		
3.	Age: Date of B	Sirth:	
4.	Educational Level:	Wishort Cords	Completed / Degree
r	Olisatia Danasat Addasas.	nighest Grade	Completed / Degree
5.	Client's Present Address:	St	treet
		Town	State
6.	Client's Permanent Address	S:	treet
		St	reet
		Town	State .
7.	Describe Current Residence	: Private Home	Group Home
		- Nursing Home	
		Hospital	Other
8.	Client's Marital Status	Single	
0,	CITCHE S HATTER DECEMBER	Married	Divorced Widowed
9.	Name and Address: Respons		Parents, Spouse, Legal Guardia
			(Circle one)
10.	Occupation: (Present/curr	ent):	
	Actively Enga (More than 5	iged No	ot involved Partial (Less than50%
11.	Training Background:		
			•
I. REI	LEASE DATA FROM W.S.S.H.:		
		(Month)	(Day) (Year)
	leased to:		

IV.	MEN	VTAL HEALTH CENTER DATA:
	a)	Primary Diagnosis:
	.p)	Secondary Diagnosis:
	c)	Prognosis:
	σ,	Prognosis:
۷.		OICATION: (Name of Drugs / Dosage / Frequency) At the Time of Release From W.S.S.H:
	-,	
	b)	Presently (Last Recorded Entry)
/I.	c) MEN	Does this reflect a change in level? (+) (-) (o) TAL HEALTH CENTER:
	_	Client's Case Manager: (Name)
		,
	b)	Manager's Professional Title:
	c)	Manager's Responsibilities to Client:
r 7	aun	DENT TREATMENT BLAN FOR OUTENS.
II.		RENT TREATMENT PLAN FOR CLIENT:
	1.	Long Range Goals:
	la.	Intermediate Objectives:
	lb.	
	lc	1

2a.	Intermediate Objectives:
2b.	
2c.	
3.	Provisions for Monitoring and Evaluation: Yes No
	HEALTH CENTER CLIENT CONTACT SUMMARY (Exit to Present) Number of Contacts: (Total number)
	Contact Schedule: Daily, weekly, monthly (Circle one) Other:
3.	Purpose of Contacts:
	ANAGER INTERVIEW REGARDING CLIENTS: Program Follow-up Suitability:
	ANAGER INTERVIEW REGARDING CLIENTS: Program Follow-up Suitability:
1.	ANAGER INTERVIEW REGARDING CLIENTS: Program Follow-up Suitability:
2.	ANAGER INTERVIEW REGARDING CLIENTS: Program Follow-up Suitability:
2.	ANAGER INTERVIEW REGARDING CLIENTS: Program Follow-up Suitability: Success of Placement:
2.	ANAGER INTERVIEW REGARDING CLIENTS: Program Follow-up Suitability: Success of Placement: Problems:

Χ.	COMM	ENTS:

Date of Data Collection:

Interviewer:

APPENDIX D

SITE SURVEY: RESIDENCE

. .

SITE SURVEY

RESIDENCE	
INTERVIEWER	
INTERVIEWER	
LOCATION	
PHONE	
DATE	· · · · · · · · · · · · · · · · · · ·
CLIENT'S NAME	
	AGE
FUNCTION LEVEL (Check appropriate d	
TOILET TRAINED	MAXIMUM SUPERVISION NEEDED
AMBULATO RY	MINIMUM SUPERVISION NEEDED
DRESS SELF	MODERATE SUPERVISION
FEED SELF	
COMMENTS:	
	•
	A content of the cont

CHECK FACILITY WHERE RESIDENT IS CURRENTLY LIVING

P R	ESENT	
	NE HOME	
1.	Number of Residents in Home	Age Span
2.	Number of House Parents	
3.	Length of Residence	
4.	How Supported	
FOS	TER HOME	
1.	Number of Foster Parents	
2.	Number of Parents	
3.	Number of Siblings	Ages
4.	Length of Residence	
5.	How Supported	
FAM	IILY	
1.	Number of Relatives	
2.	Number of Parents	
3.	Number of Siblings	Ages
4.	Length of Residence	
5.	How Supported	
SER	MI-INDEPENDENT	
1.	Roomate Spouse	Λ1one
2.	How Financially Supported	
3.	Type of Supervision	
	Frequency of Visits	
4.	Length of Residence	
NU	RSING HOME	
-	Number of Total Posidents	1

2.	Number of Devel	opmer	tally Disabled Residents					
3.	Length of Resid	ence_						
	EPENDENT LIVING							
1.	RoomateS	pouse	Alone					
2.	How Financially	Supp	orted					
	Are there home visits? YesNoNA							
4.	How frequent are visits?							
			visits					
6.	Length of Resid	ence_						
отн								
			·					
			\					
PAS	T - LIST OTHER F	ACILI	TIES WHERE RESIDENT HAS LIVED SI	NCE RELEASED FROM WSSH				
1.				DATES				
2.								
_				DATES				
۷.				DATES				
CUR	RENT							
		1.	What is approximate population	of community				
		2.	Describe location of facility:					
Yes	NoNA	3.	Is there a board or advisory bo facility?	dy that supervises the				
Yes	NoNA	4.	Are there provisions for the rehome visits? How often					
		5.	Are there any colleges with whi have been established? Which o	nes?				
Yes	NoNA		Describe the relationship					

			6.	Is the resident allowed opportunity to leave the pre- mises when sufficient responsibility has been demon- strated? How often
Yes	_ No	_ NA		With escort Without escort
			7.	Are restrictions placed on the resident having personal possessions such as: personal care items, sharp or dangerous objects? List items
Yes	No	_ NA		
Yes	No	NA	8.	Is there an opportunity for the resident to earn an allowance at the facility?
			9.	List the resident's sources of money
Yes	No	NA	10.	Is the resident allowed to keep his own money?
Yes	No	NA		Does the resident participate in his own money manage- ment?
Yes	_ No	NA	12.	Are provisions taken to guarantee proper nutrition (modified diet) (dietitian's services).
			13.	Describe any different dining and serving arrangements other than family style:
			14.	Clothing: Individually owned shared Articles shared
Yes	_ No	NA		Does the resident have his/her own chest of drawers? If not, do they share?
			16.	Sleeping Arrangements:
				Number of Individuals/Room Ages
				Shared BedOwn Bed
Yes	No	NA	17.	Does resident have access to telephones for incoming and local out-going calls?
				Is resident allowed to open own mail without direct surveillance? Reason
Yes	_ No	NA ·		
Yes	_ No	NA		Does the resident have an opportunity to participate in the formation of facility policies and procedures?
PROFE	SSIONA	L QUALIE	TICATI	ON OF RESIDENCE SUPERVISORS:
1	. Edu	cation_		(Supervisor or Parent's Name)
		erience		
L	- nvh			

3.	Trai	ning spe	cifi	to job
4.	Year	s in cur	rent	position
RESIDE	NT TPA	INING PR	OGRAI	ા
Yes	No	NA	1.	Does the current training program provide for continous evaluation and assessment? Describe
		NA	2.	Does the current training program contain specific objectives?
Yes	No	NA	3.	Does the training program contain exit and entry criteria?
			4.	What is the expected outcome for this client?
Yes	No	. NA		Is a written comprehensive training program for the individual in evidence?
PROFES	SIONAL	QUALIFI	CATI	ON OF RESIDENCE SUPERVISORS: (Supervisor or Parent's Name)
				(Supervisor or Parent's Name)
3.	Trai	ning spe	cifi	c to job
4.	Year	s in cur	rent	position

LEISURE TIME

	LEIS		E			
	CLIENT PARA	TCIPATION	FREQ	FREQUENCY		
ACTIVITIES	Rasidence! I	Day Project	Residence	Day Project		
Field Trips	1					
Movies	:		1	i		
Telavision				1		
Sports Events						
Dances			ì	1		
Records, Radio			1	1		
Music			Ş			
Camping/Hiking				7		
Gardening				i		
Bowling			1			
Bicycling			}			
Cooking			}	1		
Sewing	1		i			
Woodworking	}		3			
Reading	{		•			
Model Building			\ \	1		
Parties			!	1		
Swimming	!		!			
Arts & Crafts			1,			
P.E. Activities	į į			1		
Celebration of	1					
Holidays & Birthdays	4					
Ice Skating	1			1		
Sledding	1			1		
Motorcycle Riding	;			1		
Fishing	! !					
Boating						
Dating				1		
Eating, Restaurant	;			1		
Other	!			ì		
		3				
	1					
	<u> </u>					

* Example 2/WK

•		PPORT	SERVICES	1		
	AVAILAE	SILITY IN	SERVICES REQUIRED	NO. CONTACTS	JAST CONTACT	
	COMMUN	VITY	BY INDIVIDUAL	PER MO. PER YR.	DATE	
	Yes	No				
Audiology						
Dentistry						
Medical						
Education						
Food/Nutrition						
Library		,				
Nursing.	· · · · · · · · · · · · · · · · · · ·					
Occupational Therapy						
Physical Therapy						
Psychological Therapy						
Activity Therapies	Activity Therapies					
(Music, Art, Dance)				·		
Social Work		3			1	
Vo. Reliab. Counseling!			,	1		
Speech Pathology		}	}			
Volunteer Services		· · · · · · · · · · · · · · · · · · ·				
Optimologist ;		;		i		

APPENDIX E

SITE SURVEY: TRAINING PROGRAM

1. .-

APPENDIX E

SITE SURVEY

TRAINING PROGRAM	
INTERVIEWER	
INTERVIEWER	
LOCATION	
CLIENT'S NAME	
BIRTHDATE	· AGE_
FUNCTION LEVEL (Check appropri	iate description)
TOILET TRAINED	MAXIMUM SUPERVISION NEEDED_
AMBULATORY	MINIMUM SUPERVISION NEEDED
DRESS SELF	MODERATE SUPERVISION
FEED SELF	
COMMENTS:	
<u> </u>	

FACILITY WHERE CLIE	INT IS PRESENT	LY RECEIVENC TEA	ENENG:	
Name of Facility				
Day Care				
Sheltered Wo	irkshop			
Work Activit	y Center			
Employed				
Other				
1. Number of Clier	its Presently	Involved		
2. Age Span of Par	ticipants	_		
3. Number of Train	ers and Assis	tants		
4. Describe Type of	of Supervision			
5. Clients Length	in Program			
6. Anticipated Ler	igth of Stay			
7. How is the Prog	ram Supported			
	TRAI	NING PROGRAM		
DAY. PROGRA	MS			
	UTILIZED	DATES IN	HOURS DURING	017177
DESCRIPTION	BY CLIENT	ATTENDANCE	DAY	SALARY
EMPLOYED	i			-
SHELTERED WORKSHOP				
ACTIVITIES CENTER			-	
DAY CARE			,	
TRANSPORTATION			4	
OTHER				
	1			
	1			
			ing program provide essment? Describe_	for contin-
YesNoNA			1	
YesNoNA	2. Does the tives?	e current train:	ing program contain	specific objec

Yes	No	<i>N</i> 1	3.	Doe	s the training program contain specific objectives?
			4.	Wha	t is the expected outcome for this client?
Yes	No	NA	5.		a written comprehensive training program for the ividual in evidence?
PROFES	SIONAL	QUALIFI	CATIO	о ис	F TRAINING SUPERVISORS:
					(Supervisor or Parent's Name)
1.	. Educa	tion			
2.	Exper	ience			
3.	Train	ing spe	cifi	c to	job
4.	Years	in cur	rent	nos	ition
•	10423	211 002		Poo	
HAS	BEING	TON			HAS BEING NOT
,	1	TAUGH	Г	NA	SKILL TAUGHT TAUGHT INA
		•	,		1. Appropriate utilization of stores and shops
			- -		2. Appropriate utilization of
		Transaction of the control of the co	İ		recreation and leisure-time
		;	<u> </u>		facilities 3. Appropriate utilization of
		:	3	!	transportation facilities
		į	Î Î		4. Orientation and finding one's own directions
	: :	•	:		5. Safety
		1	1		6. Appropriate utilization of
	\ 				postal services 7. Appropriate utilization of
			;	!	public services (police, fire
		····	i		department, library, etc.)
			30.5		8. Budgeting/financial management skills
		i	i		9. Other specific community mobility
	1	···		·	utilization skills
TRANSP	ORTATIO	N			PARTICIPATION
DESCRI Walk	PTION	AVAIL	ABLE	IN	COMMUNITY : BY RESIDENT: SUPERVISED UNSUPERVISED
BICYCL	E	<u> </u>			
EUS		;			
TAXI				·	\$
CAR OTHER		· -			
					The state of the s

LEJSURE TIME CLIENT PARTICIPATION FREQUENCY* ACTIVITIES Residence ! Day Project Residence | Day Project Field Trips Movies Television Sports Events Dances Records, Radio Music Camping/Hiking Gardening Bowling Bicycling Cooking Sewing Woodworking Reading Model Building Parties Swimming Arts & Crafts P.E. Activities Celebration of Holidays & Birthdays Ice Skating Sledding Motorcycle Riding Fishing Boating Dating Eating, Restaurant Other * Example 2/WK PLEASE RESPOND: To what degree have these people been accepted and integrated into the community? Describe any specific problems encountered in integrating these people into a community setting: Please describe what you would consider to be the most serious problems encountered

in providing your service to this population:

Do you feel your program can accommodate more high-risk c	lients vs. lov-risk clients?
LIST OTHER FACILITIES WHERE CLIENT H'S RECEIVED TRAINING	SINCE WSSH
1	DATES
2	DATES
3	DATES
4	DATES

APPENDIX F

AAMD ADAPTIVE BEHAVIOR SCALE

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AAMD ADAPTIVE BEHAVIOR SCALE

KAZUO NIHIRA RAY FOSTER MAX SHELLHAAS HENRY LELAND

1974 Revision

Charles J. Fogelman, Editor

AAMD ad hoc Committee on the Adaptive Behavior Scale

Chairman, Arnold A. Madow Henry Leland Bruce C. Libby Kazuo Nihira

George Soloyanis, Executive Director

American Association on Mental Deficiency 5201 Connecticut Avenue, N.W. Washington, D. C. 20015

PART ONE

I. INDEPENDENT FUNCTIONING

[6] Self-Care at Toilet A. Eating (Check ALL statements which apply) [1] Use of Table Utensils (Circle only ONE) Lowers pants at the toilet without help Sits on toilet seat without help Uses knife and fork correctly and neatly 6 Uses table knife for cutting or spreading 5 Uses toilet tissue appropriately Flushes toilet after use Feeds self with spoon and fork - neatly 4 Feeds self with spoon and fork - considerable Puts on clothes without help 3 Washes hands without help spilling None of the above Feeds self with spoon - neatly Feeds self with spoon - considerable spilling B. Toilet Use ____ feeds self with fingers or must be fed () [2] Eating in Public (Circle only ONE) C. Cleanliness Orders complete meals in restaurants [7] Washing Hands and Face Orders simple meals like hamburgers or hot dogs (Check ALL statements which apply) Orders soft drinks at soda fountain or canteen Does not order at public eating places Washes hands with soap Washes face with soap [3] Drinking (Circle only ONE) Washes hands and face with water Dries hands and face Drinks without spilling, holding glass in one None of the above Drinks from cup or glass unassisted - neatly [8] Bathing (Circle only ONE) Drinks from cup or glass unassisted Prepares and completes bathing unaided considerable spilling Washes and dries self-completely without \cap Does not drink from cup or glass unassisted prompting or helping Washes and dries self reasonably well with [4] Table Manners (Check ALL statements prompting which apply) 4 Washes and dries self with help Attempts to soap and wash self 8 number Swallows food without chewing Cooperates when being washed and dried by checked = Chews lood with mouth open others Drnps tood on table or floor Makes no attempt to wash or dry self Uses napkin incorrectly or not at all Talks with mouth full [9] Personal Hygiene takes food off others' plates (Check ALL statements which apply) Eats too fast or too slow Plays in food with fingers Has strong underarm odor None of the above 4 number Does not change underwear regularly by self Does not apply, e.g., because he or she is checked Skin is often dirty if not assisted bedfast, and/or has liquid foud only. (If Does not keep nails clean by self checked, enter "0" in the circle to the right) None of the above Does not apply, e.g., because he or A. Eating she is completely dependent on others. (If checked, enter "O" in the circle to the right.) B. Toilet Use [10] Tooth Brushing (Circle only ONE) [5] Toilet Training (Circle only ONE) Applies toothpaste and brushes teeth with up Never has toilet accidents and down motion 5 Never has toilet accidents during the day Applies toothpaste and brushes teeth Occasionally has toilet accidents during the day 2 Brushes teeth without help, but cannot apply Frequently has toilet accidents during the day toothpaste Is not toilet trained at all 2 Brushes teeth with supervision Cooperates in having teeth brushed () Makes no attempt to brush teeth 3

[11] Menstruation (Circle only ONE)	F. Dressing and Undressing
(For males, Circle ''no menstruation'')	[15] Dressing (Circle only ONE)
No menstruation 5	
Cares for self completely for menstruation without 5	Completely dresses self 5 Completely dresses self with verbal prompting
assistance or reminder	only 4
Cares for self reasonably well during menstruation Helps in changing pads during menstruation 3	Dresses self by pulling or putting on all clothes
Indicates pad needs changing during menstruation 2	with verbal prompting and by fastening
Indicates that menstruation had begun 1	(zipping, buttoning, snapping) them with help 3
Will not care for self or seek help during	Dresses self with help in pulling or putting on
nienstruation 0	most clothes and fastening them 2
C Cleanliness ADD	Cooperates when dressed by extending arms or
7.11	legs 1 Must be dressed completely 0
	Wast the dressed completely
D. Appearance	[16] Undressing at Appropriate Times
[12] Posture (Check ALL statements which apply)	(Circle only <u>ONE</u>)
-	Completely undresses self 5
Mouth hangs open	Completely undresses self with verbal
Head hangs down Stomach sticks out because of posture 8-number	prompting only 4
Shoulders slumped forward and bark bent checked =	Undresses self by unfastening (unzipping,
Walks with toes out or toes in	unbuttoning, unsnapping) clothes with help and
Walks with feet far apart	pulling or taking them off with verbal prompting 3 Undresses self with help in unfastening and
Shuffles, drags, or stamps feet when walking	pulling or taking off most clothes 2
Walks on tiptoes	Cooperates when undressed by extending arms
None of the above	or legs 1
Does not apply, e.g., because he or she is	Must be completely undressed 0
bedfast or non-ambulatory (If checked, enter "0" in the circle to the right.)	
enter of in the circle to the right	[17] Shoes (Check ALL statements with apply)
[13] Clothing (Check ALL statements which apply)	Puts on shoes correctly without assistance
	Ties shoe laces without assistance
Clothes do not fit properly if not assisted	Unties shoe laces without assistance
Wears torn or unpressed clothing if not prompted	Removes shoes without assistance
Rewears dirty or soiled clothing if not prompted 7-number	None of the above
prompted checked =	\wedge
Does not know the difference between work	F. Dressing and UndressingADD /
shoes and dress shoes (15-17
Does not choose different clothing for formal	
and informal occasions	
Does not wear special clothing for different	
weather conditions (raincoat, overshoes, etc.) None of the above	G. Travel
Does not apply, e.g., because he or she is	(19) Songe of Direction (Circle only ONE)
completely dependent on others (If checked,	[18] Sense of Direction (Circle only ONE)
enter "0" in the circle to the right)	Goes a few blocks from hospital or school
D. AppearanceADD	ground, or several blocks from home without
12-13	getting lost 3
E. Care of Clothing	Goes around hospital ground or a few blocks
L. Care or Clothing	from home without getting lost 2
[14] Care of Clothing	Goes around cottage, ward, or home alone
(Check ALL statements which apply)	Gets lost whenever leaving own living area 0
Wipes and polishes shoes when needed	
Puts clothes in drawer or chest neatly	
Sends clothes to laundry without being reminded	
Hangs up clothes without being reminded None of the above	
/	

E. Care of Clothing _

[19] Public Transportation (Check ALL statements which apply)	II. PHYSICAL DEVELOPMENT	
Rides on train, long-distance bus or plane independently Rides in taxi independently	A. Sensory Development (Observable functioning ability)	
Rides subway or city bus for unfamiliar journeys	[22] Vision (With glasses, if used) (Circle only ONE)	
Rides subway or city bus for familiar journeys	Nn difficulty in seeing	3
None of the above	Some difficulty in seeing	$\frac{3}{2}$
Addition the above	Great difficulty in seeing	1 (
ADD /	No vision at all	0
G. Travel		
(0.1)	[23] Hearing (With hearing aid, if used) (Circle only <u>ONE</u>)	
H. Other Independent Functioning	No difficulty in hearing	3
	Some difficulty in hearing	$\frac{1}{2}$
[20] Telephone (Check ALL statements which	Great difficulty in hearing	1
apply)	No hearing at all	0
Uses telephone directory		
Uses pay telephone	A. Sensory Development	ADD
Makes telephone calls from private telephone		22-23
Answers telephone appropriately \		
Takes telephone messages		
None of the above	0.14	
[21] Miscellaneous Independent Functioning	B. Motor Development	
(Check ALL statements which apply)	[24] Body Balance (Circle only ONE)	
Prepares own bed at night	Stands on ''tiptoe'' for ten seconds if asked	5
Goes to bed unassisted, e.g., getting in bed,	Stands on one foot for two seconds if asked	4
covering with blanket, etc	Stands without support	3
Has ordinary control of appetite, eats moderately	Stands with support	$\frac{2}{}$
Knows postage rates, buys stamps from Post	Sits without support Can do none of the above	1 0
Office	Can do none of the above	0
Looks after personal health, e.g., changes wet	toes and the	
Deals with simple injuries, e.g., cuts, burns	[25] Walking and Running (Check ALL statements which apply)	
Knows how and where to obtain a doctor's or	(Check Mee statements which apply)	
dentist's help	Walks alone	_
Knows about welfare facilities in the community	Walks up and down stairs alone	_ ()
None of the above	Walks down stairs by alternating feet	_ \ /
\wedge	Runs without falling often	
H. Other Independent Functioning ADD	Hops, skips or jumps None of the above	
20-21		
	[26] Control of Hands (Check ALL statements which apply)	
I. INDEPENDENT FUNCTIONING ADD	Carbanahall	
TRIANGLES A-H	Catches a ball Throws a ball overhand	
	Lifts cup or glass	- (
	Grasps with thumb and finger	_ ()
	None of the above	

[27] Limb Function (Check ALL statements which apply) Has effective use of right arm Has effective use of left arm Has effective use of left leg None of the above B. Motor Development ADD 24-27 II. PHYSICAL DEVELOPMENT ADD TRIANGLES A-B	Buys all own clothing 5 Buys own clothing 6 Buys own clothing accessories 4 Makes minor purchases without help (candy, soft drinks, etc.) 3 Does shopping with slight supervision 2 Does shopping with close supervision 1 Does no shopping 0 B. Shopping Skills ADD 30-31 III. ECONOMIC ACTIVITY ADD TRIANGLES A-B
III. ECONOMIC ACTIVITY A. Money Handling and Budgeting	IV. LANGUAGE DEVELOPMENT A. Expression
Uses banking facilities independently Makes change correctly but does not use banking facilities Adds coins of various denominations, up to one dollar Uses money, but does not make change correctly Does not use money 4 Add one dollar 2 Does not use money 0	Writes sensible and understandable letters Writes short notes and memos Writes or prints forty words Writes or prints ten words Writes or prints own name Cannot write or print any words 0
[29] Budgeting (Check ALL statements which apply) Saves money or tokens for a particular purpose Budgets fares, meals, etc Spends money with some planning Controls own major expenditures None of the above A. Money Handling and Budgeting ADD 28-29	[33] Preverbal Expression (Check ALL statements which apply) Nods head or smiles to express happiness indicates hunger indicates wants by pointing or vocal noises Chuckles or laughs when happy Expresses pleasure or anger by vocal noises is able to say at least a few words (Enter "6" if checked, regardless of other items) None of the above
B. Shopping Skills [30] Errands (Circle only ONE)	[34] Articulation (Check ALL statements which applyif no speech, check "None" and enter "0" in the circle) 4-number
Coes to several shops and specifies different items 4 Goes to one shop and specifies one item 3 Goes on errands for simple purchasing without a note 2 Goes on errands for simple purchasing with a note 1 Cannot be sent on errands 0	Speech is low, weak, whispered or difficult to hear Speech is slowed, deliberate or labored Speech is hurried, accelerated, or pushed Speaks with blocking, halting, or other irregular interruptions None of the above

[35] Sentences (Circle only ONE)	C. Social Language Development
Sometimes uses complex sentences containing thecause," "but," etc. Asks questions using words such as "why," "how," "what," etc. Speaks in simple sentences. Speaks in primitive phrases only, or is non-verbal.	39 Conversation (Check ALL statements which apply) Uses phrases such as "please," and "thank you"
(36) Word Usage (Circle only ONE)	None of the above
Talks about action when describing pictures Names people or objects when describing pictures Names familiar objects Asks for things by their appropriate names Is non-verbal or nearly non-verbal A. Expression ADD 32-36	[40] Miscellaneous Language Development (Check ALL statements which apply) Can be reasoned with Obviously responds when talked to Talks sensibly Reads hooks, newspapers, magazines for enjoyment Repeats a story with little or no difficulty Fills in the main items on application form reasonably well None of the above
B. Comprehension [37] Reading (Circle only ONE)	C. Social Language ADD Development 39-40
Reads books suitable for children nine years or older 5 Reads books suitable for children seven years old 4 Reads simple stories or comics 3 Reads various signs, e.g., "NO PARKING," "ONE WAY,""MEN," WOMEN," etc 2 Recognizes ten or more words by sight 1 Recognizes fewer than ten words or none at all 0	IV. LANGUAGE DEVELOPMENT ADD TRIANGLES A-C
[38] Complex Instructions	V. NUMBERS AND TIME
(Check ALL statements which apply)	[41] Numbers (Circle only ONE)
Understands instructions containing prepositions, e.g., "on," "in," "behind," "under, etc Understands instructions referring to the order in which things must be done, e.g., "first dothen do." Understands instructions requiring a decision "If—, do this, but if not, do—" None of the above	Does simple addition and subtraction Counts ten or more objects Mechanically counts to ten Counts two objects by saying "one—two" Discriminates—between "one" and "many" or "a Int" Has no understanding of numbers 0
B. Comprehension ADD 37-38	

[42] Time (Check ALL statements which apply)	[47] Food Preparation (Circle only ONE)
Tells time by clock or watch correctly to the minute Understands time intervals, e.g., between "3-30" and "4-30" Understands time equivalents, e.g., "9-15" is the same as "quarter past nine" Associates time on clock with various actions and events None of the above [43] Time Concept (Check ALL statements which apply)	Prepares an adequate complete meal (may use canned or frozen food) Mixes and cooks simple food, e.g., fries eggs, imakes pancakes, cooks TV dinners, etc. Prepares simple foods requiring no mixing or cooking, e.g., sandwiches, cold cereal, etc. Does not prepare food at all. [48] Table Clearing (Circle only ONE) Clears table of breakable dishes and glassware. Clears table of unbreakable dishes and silverware.
Names the days of the week Refers correctly to "morning" and "afternoon" Understands difference between day-week, minute-hour, month-year, etc None of the above	B Kitchen ADD 46-48
V. NUMBERS AND TIME ADD 41-43	C. Other Domestic Activities
VI. DOMESTIC ACTIVITY	[49] General Domestic Activity (Check ALL statements which apply)
A. Cleaning [44] Room Cleaning (Circle only ONE) Cleans room well, e.g., sweeping, dusting and tidying Cleans room but not thoroughly 2 1	Washes dishes well Makes bed neatly Helps with household chores when asked Does household tasks routinely None of the above C. Other Domestic Activities ENTER
Does not clean room at all 0 [45] Laundry (Check ALL statements which apply)	VI DOMESTIC ACTIVITY ADD
Washes clothing Dries clothing Folds clothing Irons clothing when appropriate None of the above A. Cleaning	VII. VOCATIONAL ACTIVITY
	[50] Job Complexity (Circle only ONE)
B. Kitchen [46] Table Selting (Circle only ONE) Places all eating utensils, as well as napkins, salt pepper, sugar, etc., in positions learned Places plates, glasses, and utensils in positions learned 2	Performs a job requiring use of tools or machinery, e.g., shop work, sewing, etc. Pertorms simple work, e.g., simple gardening, mopping floors, emptying trash, etc. Pertorms no work at all.

Places silver, plates, cups, etc., nn the table

Does not set table at all

	B. Perseverance
[51] Job Performance	[55] Attention (Circle only ONE)
(Check ALL statements which apply)	
(If "O" is circled in item 50, check "None of	Will pay attention to purposeful activities for
the above" and enter "0" in the circle). 4-number	more than fifteen minutes, e.g., playing
Endangers others because of carelessness checked =	games, reading, cleaning up 4
Does not take care of tools —	Will pay attention to purposeful activities for at
ls a very slow worker (least fifteen minutes
Does sloppy, inaccurate work	Will pay attention to purposeful activities for at
None of the above	least ten minutes Will pay attention to purposeful activities for at
	least five minutes
	Will not pay attention to purposeful activities
[52] Work Habits	for as long as five minutes 0
(Check ALL statements which apply)	[56] Persistence
(If "O" is circled in item 50, check "None of	(Check ALL statements which apply) 4-number
the above" and enter "0" in the circle) Is late from work without good reason. 5-number	Becomes easily discouraged checked =
Is late from work without good reason Is often absent from work	Fails to carry out tasks
Does not complete jobs without constant	Jumps from one activity to another
encouragement	Needs constant encouragement to complete task
Leaves work station without permission	None of the above
Grumbles or gripes about work	Does not apply, e.g., because he or she is
None of the above	totally incapable of any organized activities
	(If checked, enter "0" in the circle to the
NUL MOCATIONAL ACTIVITY ADD	right) B. Perseverance ADD .
VII. VOCATIONAL ACTIVITY	B. Perseverance ADD
50-52	33-36 2
	C. Leisure Time
VIII. SELF-DIRECTION	C. Leisure Time
VIII. SELF-DIRECTION	[57] Leisure Time Activity
A. Intalnation	(Check ALL statements which apply)
A. Initiative	
[53] Initiative (Circle only ONE)	Organizes leisure time on a fairly complex
	level, e g , plays billiards, fishes, etc
Initiates most of own activities, e.g.,	Has hobby, e.g., painting, embroidery,
tasks, games, etc.	collecting stamps or coins Organizes leisure time adequately on a simple
Asks if there is something to do, or	level, e.g., watching television, listening
explores surroundings, e.g., home, yard, etc. 2	to phonograph, radio, etc
Will engage in activities only if assigned or	None of the above
directed 1	
Will not engage in assigned activities, e.g.,	C. Leisure TimeENTER_
putting away toys, etc	57
[54] Passivity	
(Check ALL statements which apply)	VIII. SELF-DIRECTION ADD
	TRIANGLES A-C
Has to be made to do things 6-number	THE THE PARTY OF T
Has no ambition checked =	
Seems to have no interest in things	IX. RESPONSIBILITY
Finishes task last because of wasted time ((50) 0 101 1 10 10 1
Is unnecessarily dependent on others for help — — —	[58] Personal Belongings (Circle only ONE)
Movement is slow and sluggish	West day till to a large of
None of the above	Very dependablealways takes care of
Does not apply, e.g., because he or she is totally dependent on others	personal belongings Usually dependable—usually takes care of
(If checked, enter ''0'' in the circle	personal belongings 2
to the right)	Unreliable-seldom takes care of personal
A	belongings 1
A. InitiativeADD	Not responsible at all-does not take care of
53-54 Similative	personal belongings ()

[59] General Responsibility (Circle only ONE)	[63] Interaction With Others (Circle only ONE)
Very conscientious and assumes much responsibility-makes a special effort, the assigned activities are always performed 3 Usually dependable-makes an effort to carry out	Interacts with others in group games or activity Interacts with others for at least a short period ot time, e.g., showing or offering toys, clothing or objects
responsibility, one can be reasonably certain that the assigned activity will be performed 2	Interacts with others imitatively with little interaction 1
Unreliablemakes little effort to carry out responsibility; one is uncertain that the assigned activity will be performed Not given responsibility; is unable to carry out	Does not respond to others in a socially acceptable manner 0
responsibility at all 0 IX. RESPONSIBILITY ADD	[64] Participation in Group Activities (Circle only ONE)
58-59	Initiates group activities (leader and organizer) Participates in group activities spontaneously and eagerly (active participant) 2
X. SOCIALIZATION	Participates in group activities if encouraged to do so (passive participant)
[60] Cooperation (Circle only ONE)	Does not participate in group activities 0
Offers assistance to others Is willing to help if asked Never helps others 2 1 0	[65] Selfishness (Check <u>ALL</u> statements which apply)
[61] Consideration for Others (Check ALL statements which apply)	Refuses to take turns — checked= Does not share with others Gets mad if he does not get his way — —
Shows interest in the affairs of others Takes care of others' belongings	Interrupts aide or teacher who is helping another person
Directs or manages the affairs of others when needed Shows consideration for others' feelings None of the above	Does not apply, e.g., because he or she has nosocial interaction or is protoundly withdrawn. (If checked, enter "0" in the circle to the right)
[62] Awareness of Others	[66] Social Maturity
(Check ALL statements which apply)	(Check <u>ALL</u> statements which apply)
Recognizes own family Recognizes people other than family	Is too familiar with strangers — 5-number checked: Is afraid of strangers — Does anything to make triends
Has information about others, e.g., job, address, relation to self. Knows the names of people close to him, e.g.,	Likes to hold hands with everyone Is at someone's elbow constantly None of the above
Classmates, neighbors Knows the names of people not regularly encountered	Does not apply, e.g., because he or she has no social interaction or is profoundly withdrawn. (If checked, enter "0" in the circle to the right.)
None of the above	
	X. SOCIALIZATION ADD 60-66
	30 00

INSTRUCTIONS FOR PART TWO

Part Two contains only one type of item. The following is an example.

[2] Damages Personal Property	Occasionally	Frequently
Rips, tears, or chews own clothing	1	2
Soils own property	1	2 (5)
Tears up own magazines, books, or other possessions	1	2
Other (specify)	1	2
None of the above	Total	4

Select those of the statements which are true of the individual being evaluated, and circle (1) if the behavior occurs occasionally, or (2) if it occurs frequently. Check "None of the Above" where appropriate. In scoring, total each column on the bottom (Total) line, and enter the sum of these totals in the circle to the right. When "None of the above" is checked, enter 0 in the circle to the right. In the above example, the first statement is true occasionally, and the last two statements are true frequently; therefore, a score of 5 has been entered.

"Occasionally" signifies that the behavior occurs once in a while, or now and then, and "Frequently" signifies that the behavior occurs quite often, or habitually.

Use the space for "Other" when:

- 1. The person has related behavior problems in addition to those circled
- 2 The person has behavior problems that are not covered by any of the examples listed.

The behavior listed under "Other" must be a specific example of the behavior problem stated in the item.

Some of the items in Part Two describe behaviors which need not be considered maladaptive for very young children (for example, pushing others). The question of whether a given behavior is adaptive or maladaptive depends on the way that particular behavior is viewed by people in our society. Nonetheless, in completing this Scale you are asked to record a person's behavior as accurately as possible, ignoring, for the moment, your personal biases; then, when you later interpret the impact of the reported behaviors, you should take into consideration societal attitudes

PART TWO

I VIOLENT AND DESTRUCTIVE BEHAVIOR

Occasionally [1] Threatens or Does Physical Violence	Frequently	Occasionally [5] Has Violent Temper, or Temper Tantrums	Frequently
Uses threatening gestures Indirectly causes injury to others Spits on others Pushes, scratches or pinches others Pulls others' hair, ears, etc Bites others Kicks, strikes or slaps others Throws objects at others Chokes others Uses objects as weapons against others Hurts animals Other (specify None of the above 1	2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	Cries and screams Stamps feet while banging objects or slamming doors, etc Stamps feet, screaming and yelling Throws self on floor, screaming and yelling Other (specify	2 2 2 2 2 2
		II. ANTISOCIAL BEHAVIOR	
Rips, tears or chews own clothing 1 Soils own property 1 Tears up own magazines, books, or other possessions 1 Other (specify 1) 1 None of the above Total	2 2 2 2	Gossips about others Tells untrue or exaggerated stories about others Teases others Picks on others Makes fun of others Other (specify None of the above Total	2 2 2 2 2 2 2
Rips, tears, or chews others' clothing 1 Soils others' property 1 Tears up others' magazines, books, or personal possessions 1 Other (specify	2 2 2 2	[7] Bosses and Manipulates Others Tries to tell others what to do 1 Demands services from others 1 Pushes others around 1 Causes fights among other people 1 Manipulates others to get them in trouble 1 Other (specify 1 None of the above 1 Total	2 2 2 2 2 2 2
property Is overly rough with furniture (kicks, mutilates, knocks it down) Breaks windows Stuffs toilet with paper, towels or other solid objects that cause an overflow Attempts to set fires Other (specify) None of the above	2 2 2 2 2 2 2	[8] Disrupts Others' Activities Is always in the way Interferes with others' activities, e.g., by blocking passage, upsetting wheelchairs, etc. 1 Upsets others' work Knocks around articles that others are working with, e.g., puzzles, card games, etc. 1 Snatches things out of others' hands Other (specify) None of the above Total	2 2 2 2 2 2 2 2

Uses hostile language, e.g., "stupid 2 jerk," "dirty pig," etc Swears, curses, or uses obscene language 2 Yells or screams threats of violence 2

Verbally threatens others, suggesting physical 2 violence Other (specify _ 2 ----None of the above Total

II. ANTISOCIAL	BEHAVIOR .	ADD	
/ // / / / / / / / / / / / / / / /		6-11	

[15] Is Absent From, or Late For, the

Is late to required places or activities	1	2
Fails to return to places where he is supposed to be after leaving, e.g., going	to	
toilet, running an errand, etc Leaves place of required activity without	1	()
permission, e.g., work, class, etc. Is absent from routine activities, e.g.,	1	2
work, class, etc Stays out late at night from home, hospital	1	2
ward, dormitory, etc	1	2
Other (specify)	1	2
None of the above Tota	I	

	V. WITHDRAWAL	
[16] Runs Away or Attempts to Run Away		
Attempts to run away from hospital, home, or school ground 1 2	[20] Is Inactive	Occasionally Frequently
Runs away from group activities, e.g., picnics, school buses, etc. 1 2	Sits or stands in one position for a long	
Runs away from hospital, home, or	period of time	1 2
school ground 1 2 Other (specify) 1 2	Does nothing but sit and watch others Falls asleep in a chair	$\begin{array}{cccccccccccccccccccccccccccccccccccc$
Other (specify 1 2 2 None of the above	Lies on the floor all day	1 2 (
Total	Does not seem to react to anything	1 2
	Other (specify)	$\frac{1}{2}$
[17] Misbehaves in Group Settings	None of the above	Total
Interrupts group discussion by talking	(04) A M/H d	
about unrelated topics 1 2 Disrupts games by refusing to follow rules 1 2	[21] Is Withdrawn	
Disrupts group activities by making loud	Seems unaware of surroundings	1 2
noises or by acting up 1 2	Is difficult to reach or contact	1 2
Does not stay in seat during lesson period,	Is apathetic and unresponsive in feeling	$\frac{1}{2}$
lunch period, or other group sessions 1 2	Has a blank stare	$\begin{array}{ccc} 1 & 2 \\ 1 & 2 \end{array}$
Other (specify 1 2 Total Total	Has a fixed expression Other (specify)	1 2
		otal
400		
III. REBELLIOUS BEHAVIOR	[22] Is Shy	
12-1/	to timed and shown social situations	1 2
	Is timid and shy in social situations Hides face in group situations, e.g., parties, informal gatherings, etc.	1 2
	Does not mix well with others	1 2
IV. UNTRUSTWORTHY BEHAVIOR	Prefers to be alone	1 2
	Other (specify)	$\frac{1}{2}$
[18] Takes Others' Property Without Permission	None of the above T	otal .
Has been suspected of stealing 1 2		
Takes others' belongings if not kept in	V. WITHDRAWAL	ADD
place or locked 1 2 Takes others' belongings from pockets.		20-22
purses, drawers, etc 1 2		
Takes others' belongings by opening or		
breaking locks 1 2		
Other (specify)	VI. STEREOTYPED BEHAV AND ODD MANNERISM	
[19] Lies or Cheats	[23] Has Stereotyped Behaviors	
Towards and a second of second	Drums fungars	1 2
Twists the truth to own advantage 1 2 Cheats in games, tests, assignments,	Drums fingers Taps feet continually	1 2
etc 1 2	Has hands constantly in motion	1 2
Lies about situations 1 2	Slaps, scratches, or rubs self continually	1 2
Lies about self 1 2	Waves or shakes parts of the body repeatedly	1 2 ()
Lies about others 1 2 Other (specify) 1 2	repeatedly Moves or rolls head back and forth	$\frac{1}{1}$ $\frac{2}{2}$
Other (specify) 1 2None of the above Total	Rocks body back and furth	1 2
	Paces the floor Other (specify)	1 2 1 2
	Other Cipi city	

None or the above

Total

Occasionally Frequently IX. UNACCEPTABLE OR [24] Has Peculiar Posture or Odd ECCENTRIC HABITS Mannerisms Occasionally Frequently Holds head tilted 2 Sits with knees under chin-[27] Has Strange And Unacceptable 2 Walks on tiptoes Habits Lies on floor with feet up in the air. Walks with fingers in ears or with Smells everything 2 hands on head Inappropriately stutfs things in pockets Other (specify shirts; dresses or shoes) ----None of the above Pulls threads out of own clothing 2 Plays with things he is wearing, e.g., shoe string, buttons, etc. VI. STEREOTYPED BEHAVIOR . 2 Saves and wears unusual articles, e.g., AND ODD MANNERISMS safety pins, bottle caps, etc 2 Hoards things, including foods 2 Plays with spit 2 Plays with feces or urine Other (specify _____ VII. INAPPROPRIATE INTERPERSONAL --- None of the above Total **MANNERS** [25] Has Inappropriate Interpersonal Manners [28] Has Unacceptable Oral Habits Talks too close to others' faces Drools 2 Blows on others' faces Crinds teeth audibly 2 Burps at others 2 Spits on the floor 2 Kisses or licks others 2 Bites fingernails 2 Hugs or squeezes others Chews or sucks fingers or other parts Touches others inappropriately . of the body 2 Hangs on to others and does not let go Chews or sucks clothing or other Other (specify _____ inedibles 2 None of the above Eats inedibles 2 Drinks from toilet stool 2 **ENTER** Puts everything in mouth VII. INAPPROPRIATE Other (specify INTERPERSONAL MANNERS --- None of the above [29] Removes or Tears Off Own VIII. UNACCEPTABLE VOCAL HABITS Clothing [26] Has Disturbing Vocal or Tears off buttons or zippers Speech Habits Inappropriately removes shoes or socks Undresses at the wrong times 2 Giggles hysterically 2 Takes off all clothing while on the toilet Talks loudly or yells at others 2 Tears off own clothing Talks to self loudly 2 2 Refuses to wear clothing Laughs inappropriately 2 Other (specify ____ Makes growling, humming, or other --- None of the above unpleasant noises 2 Total Repeats a word or phrase over and over 2 Mimics others' speech 2 Other (specify None of the above

VIII UNACCEPTABLE VOCAL

HABITS

BEHAVIOR

[30] Has Other Eccentric Habits and Tendencies Occasionally Frequently Is overly particular about places to sit [33] Engages in Inappropriate or sleep Masturbation Stands in a lavorite spot, e.g., by window, by door, etc. Has attempted to masturbate openly Sits by anything that vibrates Masturbates in front of others Is alraid to climb stairs or to go Masturbates in group down stairs Other (specify _ 1 Does not want to be touched 2 ----None of the above Screams if touched Total Other (specify ___ ___ None of the above [34] Exposes Body Improperly Total Exposes body unnecessarily after IX UNACCEPTABLE OR using toilet 2 ECCENTRIC HABITS Stands in public places with pants down or with dress up-Exposes body excessively during activities, e.g., playing, dancing, sitting, etc. Undresses in public places, or in X SELF-ABUSIVE BEHAVIOR front of lighted windows Other (specify _____ [31] Does Physical Violence to Self ---- None of the above Total Bites or cuts self Slaps or strikes self [35] Has Homosexual Tendencies Bangs head or other parts of the body against objects 2 Is sexually attracted to members of Pulls own hair, ears, etc. 2 the same sex Scratches or picks self causing injury Has approached others and attempted Soils and smears self homusexual acts 2 Purposely provokes abuse from others Has engaged in homosexual activity 2 Picks at any sores he might have Other (specify _____ Pokes objects in own ears, eyes nose, or -----None of the above mouth Total Other (specify _ ---- None of the above Total [36] Sexual Behavior That Is Socially Unacceptable X SELF-ABUSIVE BEHAVIOR _ Is overly seductive in appearance or 2 actions Hugs or caresses too intensely in public 2 XI. HYPERACTIVE TENDENCIES Needs watching with regard to 2 sexual behavior [32] Has Hyperactive Tendencies Lifts or unbuttons others' clothing to touch intimately Talks excessively Has sexual relations in public places Will not sit still for any length of time Is overly aggressive sexually. Constantly runs or jumps around the room Has raped others Is easily taken advantage of sexually Moves or hidgets constantly Other (specify _____ Other (specify None of the above ___ None of the above Total ADD XII. SEXUALLY ABERRANT

XI HYPERACTIVE TENDENCIES ENTER

	Occasional	lly Frequently	[42] Has Hypochondriacal tendencies
[37] Tends to Overestimate Own Ab Does not recognize own limitations Has too high an opinion of self Talks about future plans that are unrealistic Other (specify None of the above		2 2 2	Complains about imaginary physical ailments Pretends to be ill Acts sick after illness is over Other (specify None of the above Total [43] Has Other Signs of Emotional Instabilities
[38] Reacts Poorly to Criticism Does not talk when corrected Withdraws or pouts when criticized Becomes upset when criticized Screams and cries when corrected Other (specify) None of the above	1 - 1 1 1 - 1 Total	2 2 2 2 2 2	Changes mood without apparent reason 1 2 Complains of bad dreams 1 2 Cries out while asleep 1 2 Cries for no apparent reason 1 2 Seems to have no eniotional control 1 2 Vomits when upset 1 2 Appears insecure or frightened in daily activities 1 2 Lalks about people or things that
Blames own mistakes on others Withdraws or pouts when thwarted Becomes upset when thwarted Throws temper tantrums when does not get own way Other (specify) None of the above	1 1 1 Total	2 2 2 2 2	Talks about suicide Has made an attempt at suicide Other (specify)
40 Demands Excessive Attention or Praise Wants excessive praise 15 jealous of attention given to others 16 Demands excessive reassurance 17 Acts silly to gain attention 17 Other Ispecity 17 Other Ispecity 18 Other Ispecity 19 Ot	1 1 1 1 1 1 Total	2 2 2 2 2	VIV. USE Of MEDICATIONS [44] Use of Prescribed Medication Uses tranquilizers 1 2 Uses sedatives 1 2 Uses anticonvulsant drops 1 2 Uses stimulants 1 2 Other (specify 1 2 None of the above Total
Complains of unfairness, even when equal shares or privileges have be given Complains. Nobody loves me'' Says. Everybody picks on me'' Says. People talk about me'' Says, 'People are against me'' Acts suspicious of people Other (specify) None of the above	1 1 1 1 1 1 1 1 Total	2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	XIV. USE OF MEDICATIONS ENTER

Identification	120
Age	
Sex	
Date of Administration	
DATA SUMMARY SHEET - AAMD ADAPTIVE BEHAVIOR SCALE PART ONE	
A. Eating B. Toilet Use C. Cleanliness D. Appearance E. Care of Clothing F. Dressing & Undressing G. Travel H. General Independent Functioning I. INDEPENDENT FUNCTIONING A. Sensory Development B. Motor Development	
II. PHYSICAL DEVELOPMENT	
A. Money Handling and Budgeting B. Shopping Skills III. ECONOMIC ACTIVITY	
A. Expression B. Comprehension C. Social Language Development IV. LANGUAGE DEVELOPMENT	
V. NUMBERS AND TIME	
A. Cleaning B. Kitchen Duties C. Other Domestic Activities	
VI. DOMESTIC ACTIVITY	→ VI
VII. VOCATIONAL ACTIVITY	→ vii
A. Initiative B. Perseverance C. Leisure Time	

VIII

IX

VIII. SELF-DIRECTION

RESPONSIBILITY

SOCIALIZATION

DATA SUMMARY SHEET

PART TWO

I.	VIOLENT AND DESTRUCTIVE BEHAVIOR	1
11.	ANTISOCIAL BEHAVIOR	//
111.	REBELLIOUS BEHAVIOR	111
IV.	UNTRUSTWORTHY BEHAVIOR	IV
V.	WITHDRAWAL	V
VI.	STEREOTYPED BEHAVIOR AND ODD MANNERISMS	VI
VII.	INAPPROPRIATE INTERPERSONAL MANNERS	VII
VIII.	UNACCEPTABLE VOCAL HABITS	VIII
IX.	UNACCEPTABLE OR ECCENTRIC HABITS	IX
Х.	SELF-ABUSIVE BEHAVIOR	X
XI.	HYPERACTIVE TENDENCIES	ΧI
XII.	SEXUALLY ABERRANT BEHAVIOR	XII
XIII.	PSYCHOLOGICAL DISTURBANCES	XIII
XIV.	USE OF MEDICATIONS	XIV

Identification	
Age	
Sex	
Date of Administration	
DATA SUMMARY SHEET - AAMD ADAPTIVE BEHAVIOR SCALE PART ONE	
A. Eating B. Toilet Use C. Cleanliness D. Appearance E. Care of Clothing F. Dressing & Undressing G. Travel H. General Independent Functioning I. INDEPENDENT FUNCTIONING A. Sensory Development B. Motor Development II. PHYSICAL DEVELOPMENT A. Money Handling and Budgeting B. Shopping Skills	i
III. ECONOMIC ACTIVITY	11
A. Expression B. Comprehension C. Social Language Development	
IV. LANGUAGE DEVELOPMENT	/\
V. NUMBERS AND TIME	١
A. Cleaning B. Kitchen Duties C. Other Domestic Activities	
VI. DOMESTIC ACTIVITY	V
VII. VOCATIONAL ACTIVITY	VI
A. Initiative B. Perseverance C. Leisure Time	
VIII. SELF-DIRECTION	VII
IX. RESPONSIBILITY	IX
X. SOCIALIZATION	X

DATA SUMMARY SHEET

PART TWO

1.	VIOLENT AND DESTRUCTIVE BEHAVIOR	1
11.	ANTISOCIAL BEHAVIOR	11
111.	REBELLIOUS BEHAVIOR	111
IV.	UNTRUSTWORTHY BEHAVIOR	IV
V.	WITHDRAWAL	V
VI.	STEREOTYPED BEHAVIOR AND ODD MANNERISMS	VI
VII.	INAPPROPRIATE INTERPERSONAL MANNERS	VII
VIII.	UNACCEPTABLE VOCAL HABITS	VIII
IX.	UNACCEPTABLE OR ECCENTRIC HABITS	IX
Х.	SELF-ABUSIVE BEHAVIOR	X
XI.	HYPERACTIVE TENDENCIES	ΧI
XII.	SEXUALLY ABERRANT BEHAVIOR	XII
XIII.	PSYCHOLOGICAL DISTURBANCES	XIII
XIV.	USE OF MEDICATIONS	XIV

Identification						
Age			-	 -	 	
Sex		_		 	 _	
Date of Administration _						

	PROFILE SUMMARY									
	AAMD ADAPTIVE BEHAVIOR SCALE PART ONE I II III IV V VI VII VIII IX X									
Deciles	Independent Functioning	Physical Development	Economic Activity	Language Development	Numbers & Time	Domestic Activity	Vocational Activity	Self-Direction	Responsibility	Socialization
D9 (90)										
(90) D8 (80)										
D7 (70)										
D6 (60)										
D5(50)										
D4 (40)										
D3 (30) D2										
(20) D1										
(10)										
Attained Scores										

	Identification _	
	Age _	
	Sex_	
Date of	Administration	

	PROFILE SUMMARY AAMD ADAPTIVE BEHAVIOR SCALE PART TWO													
	I	П	111	IV	V	VI	VII	VIII	IX	X	XI	XII	XIII	XIV
Deciles	Violent & Destructive Behavior	Antisocial Behavior	Rebellious Behavior	Untrustworthy Behavior	Withdrawal	Stereotyped Behavior and Odd Mannerisms	Inappropriate Inter- personal Manners	Unacceptable Vocal Habits	Unacceptable or Eccentric Habits	Self-Abusive Behavior	Hyperactive Tendencies	Sexually Aberrant Behavior	Psychological Disturbances	Use of Medications
D9 (90)														
D8 (80)														
D7 (70)														
D6 (60)														
D5 (50)								i						
D4 (40)														
(30)														
D2 (20)														
D1 (10)														
Attained Scores														

Identification	
Age	
Sex	
Date of Administration	

	PROFILE SUMMARY AAMD ADAPTIVE BEHAVIOR SCALE PART ONE									
	1	11	Ш	IV	V	VI	VII	VIII	lX	X
Deciles	Independent Functioning	Physical Development	Economic Activity	Language Development	Numbers & Time	Domestic Activity	Vocational Activity	Self-Direction	Responsibility	Socialization
ng										
D9 (90)										
D8 (80)										
(80)										
D7 (70)										
D6 (60)										
									:	
D5 (50)										
D4										
(40)										
03										
(30)										
D2(20)										
D1 (10)										
Attained Scores										

Identification	
Age	
Se×	
Date of Administration	

	PROFILE SUMMARY AAMD ADAPTIVE BEHAVIOR SCALE PART TWO													
	1	11	III	IV	V	VI	VII	VIII	lΧ	X	XI	XII	XIII	XIV
Deciles	Violent & Destructive Behavior	Antisocial Behavior	Rebellious Behavior	Untrustworthy Behavior	Withdrawal	Stereotyped Behavior and Odd Mannerisms	Inappropriate Inter- personal Manners	Unacceptable Vocal Habits	Unacceptable or Eccentric Habits	Self-Abusive Behavior	Hyperactive Tendencies	Sexually Aberrant Behavior	Psychological Disturbances	Use of Medications
nq														
(90)														
D8														
(80)														
D7 (70)														
D6 (60)														
D5 (50)														
			,											
D4 (40)														
D3														
(30)														
D2 (20)														
D1 (10)														
Attained Scores														

A A M D ADAPTIVE BEHAVIOR SCALE For Children and Adults 1974 Revision

Name(last)		(first)		Special Identification		
Date (mo)	(day)	(year)	Sex: ^M	Date of Birth (mo) (day) (year)	
Name of perso	n filling out Scale					
Source of info Physician'')	ormation and rela	ationship to person	being evaluated (su	ch as "John Doe -	Parent," or "Sel	f -
Additional Inf	ormation:					

This Scale consists of a number of statements which describe some of the ways people act in different situations. There are several ways of administering the Scale; these, and detailed scoring instructions, appear in the accompanying *Manual*.

Instructions for the second part of the Scale immediately precede the second half of this booklet.

INSTRUCTIONS FOR PART ONE

There are two kinds of items in the first part of the Scale. The first requires that you select only ONE of the several possible responses. For example:

[2] Eating in Public (Circle only ONE) Orders complete meals in restuarants Orders simple meals like hamburgers or hot dogs Orders soft drinks at soda fountain or canteen Does not order at public eating places	3 ② 1 0	2	
Does not order at public eating places	Ü		

Notice that the statements are arranged in order of difficulty: 3,2,1,0. Circle the one statement which best describes the *most difficult* task the person can usually manage. In this example, the individual being observed can order simple meals like hamburgers or hot dogs (2), but cannot order a complete dinner (3). Therefore, (2) is circled in the example above. In scoring, 2 is entered in the circle to the right.

The second type of item asks you to check ALL statements which apply to the person. For example:

[4] Table Manners (Check ALL statements which apply) Swallows food without chewing Chews food with mouth open Drops food on table or floor Uses napkin incorrectly or not at all Talks with mouth full. Takes food off others' plates Eats too fast or too slow Plays in food with fingers None of the above Does not apply, e.g., because he or she is completely dependent on		8-number checked =

In the example above, the second and fourth items are checked to indicate that the person "chews food with mouth open" and "uses napkin incorrectly." In scoring, the number of items checked, 2, is subtracted from 8, and the item score, 6, is entered in the circle to the right. Most items do not, however, require this subtraction; instead, the number checked can be directly entered as the score. The statement "None of the above," which is included for administrative purposes only, is not to be counted in scoring here.

Some items may deal with behaviors that are clearly against local regulations, (e.g., use of the telephone), or behaviors that are not possible for a person to perform because the opportunity does not exist, (e.g., eating in restaurants is not possible for someone who is bedridden). In these instances, you must still complete your rating. Give the person credit for the item if you feel absolutely certain that he or she can and would perform the behavior without additional training had he or she the opportunity to do so. Write "AR" for "Against Regulations" or "HNO" for "Has No Opportunity" next to the rating made in these cases. These notations will not affect the eventual scoring of that item, but will contribute to the understanding and interpretation of the person's adaptive behavior and environment.

Please observe the following general rules in completing the Scale:

- 1. In items which specify "with help" or "with assistance" for completion of task, these mean with direct physical assistance.
- 2. Give the person credit for an item even if he or she needs verbal prompting or reminding to complete the task unless the item definitely states "without prompting" or "without reminder."

This Scale is prepared for general use. Therefore, some of the items may not be appropriate for your specific setting, but please do try to complete all of them.

APPENDIX G

AGENCY COMMENTS AND RESPONSES

The Big Sky Country



STATE OF MONTANA

SOCIAL AND REHABILITATION SERVICES

PO BOX 4210
HELENA MONTANA 59601
October 11, 1977



THOMAS L. JUDGE GOVERNOR PATRICK E. MELBY DIRECTOR

DEVELOPMENTAL DISABILITIES DIVISION
L. A. HAMERLYNCK
ADMINISTRATOR

Pat Melby, Director Social and Rehabilitation Services 111 Sanders Helena, MT 59601

Dear Pat:

Dr. Hamerlynck has asked me to respond on behalf of the Developmental Disabilities Division to the draft report "Follow-up Survey of Mentally Ill Patients Released from WSSH."

The nature of my response must depend on the premise of the contract with Dr. Sexton, et. al. Having been involved with discussions of this study over a year ago, it is my recollection that the OBPP wanted data which could be used to evaluate the success or non-success of Montana's deinstitutionalization program. Based on this premise, the study is extremely disappointing. If, however, the eventual agreement was to do a survey to see what a sample of persons placed from WSSH were like in terms of age, sex, skill levels, location of placement, type of placement, etc., then I have few comments.

My lack of knowledge of the contract specifications notwithstanding, I will proceed to mention a number of items I feel are noteworthy.

It is not clear on page 1 how the sample was drawn. The report states that "A list of names of all patients released prior to February, 1977 was obtained from WSSH and a systematic random sample was drawn." Does this mean they had patients released in 1930, for example, in their sample? The authors state later in the summary that it included patients who left after 1970. This should be clarified.

I cannot find data anywhere in the report which summarized dates of placement for the sample. This is pertinent information since length of exposure to community living arrangements may be an important variable relating to community adjustment and skill levels.

Pat Melby, Director Page 2 October 11, 1977

I don't feel the Adaptive Behavior scale information is useful for purposes other than giving us a profile of the "typical" client in the sample. Without any pre and post-institutionalization information, it is not possible to conclude that community placement had either a beneficial or detrimental effect. In addition, I am confused about the authors' statement in this section regarding "zero responses" generated by the scale. They state "A zero response may place the sample group within the maladjusted range when in fact they do not exhibit abnormal behaviors." I don't believe this statement is correct. In Part I of the scale (Adaptive Functioning), a zero response is generated either when the client's skill level is at the lowest possible level (on "positive" items) or when "Does not apply" is checked on "negative" items which indicates that the person is completely dependent on others. This should not result in any inherent biasing or skewing of the results. In Part II of the scale (maladaptive Behaviors), a zero response is generated when "None of the above" is checked. This indicates that the client emits none of the maladaptive behaviors listed for a given item. is an inherent difficulty in that the client may have never had the opportunity to steal others' belongings in one setting and will emit the behavior subsequently in another setting, but the zero response in any event has the effect of putting the client in a more positive (adjusted) light because a higher score in Part II indicates less adaptation. One final comment regarding the ABS. On page two of the Summary and Conclusions the authors state that data were collected using the Camelot Behavior Scale. This was not mentioned earlier in the report and I wonder whether it was used or not.

I have a couple of comments about the survey results. The report found that 63% of the sample said they were satisfied with their placement situation. I find this figure alarmingly low and have to wonder how much involvement clients from WSSH have in their own placement planning. I was also amazed that only 22% of the sample were in a day training program (100% of DD clients from BRS&H are in day programs) and that only 50% of them had any written program plans. One might conclude from this that most persons in the sample did not need any day training except when one notes that 73% were seen as requiring either constant or moderate supervision.

To summarize, I feel that the survey information presented in the report is interesting and somewhat useful, but does not allow one to draw any conclusions regarding the success or non-success of the WSSH deinstitutionalization program.

Sincerely,

Richard P. Swenson, Ph.D.

Dok Swersan

cc: Dr. Hamerlynck

Date: November 1, 1977

STATE OF MONTANA DEPARTMENT OF INSTITUTIONS HELENA

To

John Fitzpatrick

Office of Budget and Program Planning

From

Lawrence M. Zanto

Director

Subject Response to the Draft Report on Deinstitutionalization of the Mentally Ill

> Enclosed please find the Department of Institution's response to the draft report submitted by Drs. Ronald P. Sexton and Elia G. Nickoloff entitled Final Evaluation and Status Report of a Follow Up Survey of a Sample of Mentally Ill Patients from Warm Springs State Hospital Who Were Released to Community Service Programs Prior to February of 1977.

> I would like to express my appreciation for the courtesy extended this Department in being able to review and comment upon this draft report.

LMZ:CC:jw

Enclosure

Department of Institutions Response to the Report entitled Final Evaluation and Status Report of a Follow Up Survey of a Sample of Mentally Ill Patients from Warm Springs State Hospital Who Were Released to Community Service Programs Prior to February, 1977 - submitted to the Office of Budget and Program Planning by Drs. Ronald P. Sexton and Elia G. Nickoloff.

The following comments on the Drs. Sexton and Nickoloff report represent a synthesis of input from staff at Warm Springs, the five Community Mental Health Centers and Mental Health and Residential Services staff. In general, the consensus is that while considerable effort was put into the development of the Final Evaluation, there are technical and conceptual flaws that seriously weaken the position of the authors in making the generalizations and conclusions presented in their report.

The dramatic shift in program emphasis and resource allocation that has accompanied the national deinstitutionalization program as well as its consequent impact on so many lives within our own state certainly merits careful scrutiny and evalution. The Department of Institutions programmatic orientation as relates to mental health services is predicated upon appropriate deinstitutionalization. Unfortunately, the <u>Final Evaluation</u> does not appear to be addressing the deinstitutionalization program in Montana, rather the focus of the report is simply upon released patients from the hospital. Although there were sporadic attempts to appropriately place patients in the community prior to 1975, Montana did not develop an organized deinstitutionalization program until 1976. The <u>Final Evaluation</u> does not take this fact into consideration.

The following is a non-exhaustive list of comments/deficiencies noted in the <u>Final Evaluation</u>.

Major Deficiencies

- 1. Perhaps the most flagrant defect noted is the size of the sample of cases employed in the report. During the period covered by the Final Evaluation (1972 first patient released through January, 1977) there were approximately 5,342 patients released from Warm Springs. The sample of 41 actual patients traced by the author represents less than 1 per cent of that number. Further, sixteen of these patients were released prior to March, 1976. The Department's program of deinstitutionalization as reflected in the Warm Springs State Hospital Patient Placement Agreement with the five Community Mental Health Centers was not begun until January, 1976 and program/ services were not started until at least March, 1976. Thus, the evaluation of the deinstitutionalization program can only focus on a sample of twenty-five patients. Unfortunately, the data in the report does not allow identification of which patients of the original 48 are the twenty-five who participated in the deinstitutionalization program.
- 2. As mentioned above, the sample size does not allow meaningful statistical analysis of the data. Therefore, inferences made or conclusions drawn from the data are open to serious questions. The frequent use of percentages to emphasize points by the author is also misleading inasmuch as the sampling error is so large that random variation by only one or two patients can change the per-

entages reported by 15-20 points.

- 3. Because deinstitutionalization is not simply removal of the patient from a hospital setting to the community, it is impossible to make any comparative statements concerning the quality of care received by the "deinstitutionalized" group without a matched sample of patients who have remained at the hospital, and/or a matched sample of patients already in community programs. In the absence of such intergroup comparisons, it is difficult to determine whether the deinstitutionalized patients were better off, worse off, or experienced no change when they were moved to community programs.
- 4. The recommendations made by the author are too general to be of much value in program planning.
- 5. The Final Evaluation is almost wholly negative. No mention is made of the extensive efforts by a number of people at various agency levels to assist these patients and to overcome considerable obstacles of funding, interagency coordination and community resistance.

Minor Deficiencies

- 1. No rationale is presented for using the time from January 1972 January 1976.
- 2. Why were no replacement or alternate cases chosen to at <u>least</u> maintain the original sample size of 58?
- 3. Although the diagnostic categories listed under <u>Diagnosis At</u>
 <u>Time of Entry Into WSSH</u>, do not conform to currently accepted
 psychiatric nomenclature, the categories listed generally came
 into use after the time of admission of many individuals in the
 sample. Therefore, the diagnoses listed must be either final
 diagnoses (diagnosis at time of release), or someone's attempt
 to rephrase diagnoses into more modern categories. This should
 be clarified.
- 4. In <u>Treatment Plan</u> at <u>WSSH</u> section, it states that chemotherapy was listed 56.9% of the time as a treatment regimen, yet in the previous section it states that "nearly 100% of the patients were using medication at the time of their release". What is the source of this discrepancy?
- 5. The section Treatment Plan Upon Release talks about a "...treatment plan for those who were released.". It is unclear whether this refers to (1) the WSSH individualized treatment plan in effect at the time of the person's discharge, (2) the proposed aftercare plan formulated by WSSH, or, (3) a treatment plan formulated for the individual by some agency other than WSSH.
- 6. The <u>Summary and Conclusions</u> section states "data collection using the Camelot and Adaptive Behavior Scale were also arranged". The "Camelot" is mentioned no place else in the report. No data from it is presented. No reference to it can be found in the most recent <u>Mental Measurements Year Book</u>, (The standard source of information concerning assessment instruments).

7. The Sample section states, "... a patient must have been hospitalized three years or longer to meet the criteria of being deinstitutionalized", and a later section states, "... the length of patient institutionalized time reflected a range of three to fifty-three years", however, Data Category 19 of Appendix B indicates that one individual in the sample was hospitalized two years or less and the length of hospitalization of two individuals in the sample was unknown.

In summary, the input received from the five community mental health centers, Warm Springs State Hospital staff and the staff of the Central Office of the Department of Institutions indicates an overall disappointment in this study; but the Department is committed to quality program evaluation efforts and offer for your consideration the following design criteria suggestions for future efforts in this area.

- 1. Test instruments should have a proven high validity and reliability.
- 2. A studies 'hypothesis/questions' should be clearly spelled out very specifically and be of research quality.
- 3. Recommendations should be very specific in nature and closely tied into the follow-up results. This report had general recommendations and the recommendations weren't tightly tied into the follow-up results.
- 4. All analysis of findings in this type of study needs to be jointly reviewed by both independent researchers <u>and</u> participating agencies. This joint analysis is needed to develop constructive recommendations, corrective steps devised for minimizing deficiencies and equally important, positive outcomes should be noted and then shared with all concerned.
- 5. Cost-efficiency studies should also be incorporated into this type study as this dimension along with quality of care are key issues in excellent service delivery.

November 9, 1977

Mr. Ted Clack Office of Budget and Program Planning Office of the Governor State of Montana Helena, MT 59601

Dear Ted:

Please find enclosed a copy of the revised report which now contains all corrections and adjustments as per your telephone feedback and our joint review of November 7, 1977.

Attached is a brief letter containing several response considerations from the study team as regards to the review letter presented under the signature of Mr. Melby and Mr. Xanto.

Sincerely,

Ronald P. Sexton, Ph.D.

Enclosure

SAMPLE SIZE

The evaluators obtained a computer printout containing the names of all patients who were released from WSSH between the dates of July 1, 1975 and February 19, 1977. July 1, 1975 being identified as the closest approximate date to the start of the "official" deinstitutionalization "campaign." The WSSH printout obtained contained a list of approximately 1400 patient names, persons identified as having been released during the stated time period.

From the list of 1400, a sub-list of all patients who had spent a minimum of three years at WSSH prior to release was generated (three consecutive years of stay being our operational definition of an institutionalized patient). This sub-list contained two hundred and ten persons. From a pool of 210, a patient study sample of sixty (29%) patients were randomly selected across the five mental health regions of the state. The study team considered twenty-nine percent of the patient pool, a sample of 60 patients a sufficient sample size.

The singular patient identified in the pool sample as having less than three years of consecutive WSSH stay was included because one source computer printout reflected the shorter length of stay, but another source (patient file) reflected a sufficiently longer period of stay.

THE COMPUTER PRINTOUT

The computer printout obtained from the WSSH data center contained a number of errors. Several being related to patient release data (Region) and patient entry and exit data. For example, the printout identified several patients having been released to Region I, when followup study found them to have been released to Region IV. Several patients found living in Region II

were relased to Region IV (according to printout data).

CONTROL GROUP

As was referenced in the text of the study report, the study team found little tangible evidence of any written objective criteria for patient release or any stated systematic procedure and criteria for deinstitutionalization. The WSSH policy appeared to be that of releasing patients when they had been determined to have received maximum benefit from the staff and resources at WSSH.

Interviews conducted at WSSH and throughout the five Mental Health Regions confirmed the above impressions. Study team efforts to identify a group of patients for pre-release study was attempted on several occasions. However, each attempt produced limited patient response (N=2) and a general reaction of "it's impossible, we don't know who or what patients will or are likely to be included in the next group or groups to be released." Thus, within the time frame of the study, we were unable to identify a patient pool for pre-release study or for the development of a control group. The proposed pre-post analysis of released patients was determined to lack feasibility under existing conditions as perceived by the study team.

